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University
of Glasgow

**Health Knowledge and Expected Outcomes of
Risky Behaviour:**
A Comparative Study of Non-Disabled Adolescents and
Young People with Intellectual and Physical Disabilities

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Division of Community Based Sciences
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Abstract

Research exploring the physical health needs of people with intellectual disabilities is increasing. Unfortunately, first hand accounts from young people with intellectual disabilities remain largely absent. This is despite the fact that many of these individuals, albeit to a lesser extent than their non-disabled peers, are engaging in behaviours that can have a potentially negative impact on their health status (poor dietary habits, excessive alcohol consumption, and risky sexual behaviour). While knowledge alone does not always result in the adoption of healthier behavioural choices, it is an important prerequisite if young people are to keep themselves safe. In addition, understanding what young people know about health is pivotal to the formulation and development of appropriate education programmes and services.

The limited research that does exist suggests that young people with intellectual disabilities have low levels of health knowledge, particularly in relation to sexual health and sexuality. Whereas public health messages are widely available concerning topics such as healthy eating and alcohol, information regarding sexual health is less accessible, owing to it being a private area of people's lives. Much of our social/sexual development is largely experiential and gained through informal routes, such as interacting with peers. Yet the social networks of young people with intellectual disabilities may be compromised, which could partly account for the low levels of sexual knowledge reported. In support of this, sexual knowledge is also limited in young people with physical disabilities, another socially excluded group. Thus, the aim of this thesis is to further our understanding of how key features of social exclusion - impoverished social networks and access to sources of health information and experience - may impact upon young people with disabilities' knowledge, attitudes and behaviour in relation to healthy eating, alcohol, pregnancy/contraception and HIV/AIDS. A substantial part of the research process was concerned with the development and piloting of appropriate methods with which to address these aims. Through structured and semi-structured questionnaires and vignette-based methodology, data from over 100 young people, aged 16-25, has been analysed and interpreted. Three groups of young people took part in the study, those with i) Intellectual disabilities (ID), ii) Physical disabilities (PD), and iii) typically developing, non-disabled (ND).

With regards to health knowledge, the ID group had the poorest scores on the healthy eating and alcohol scales. However, the largest differences between the groups were related to health issues considered to be more personal and private, such as pregnancy and contraception, with both groups of young people with disabilities having lower levels of sexual health knowledge than their non-disabled peers. Thus, deficits in sexual knowledge did not just appear to be the result of the ID group's cognitive deficits. Moreover, content analyses of open-ended questions on the questionnaire showed that all three groups held a surprising number of misconceptions about sexuality. It was also notable that young people with ID reported discussing sexual issues with friends and family less frequently than their non-disabled peers and reported being more reliant upon formal sources of sex education, such as that received through school or college. In addition, when participants with intellectual and physical disabilities were asked about how others would react to them drinking excessive amounts of alcohol and being open to a possible sexual encounter, using vignettes, they anticipated more negative attitudes from their friends for engaging in these potentially risky behaviours than their non-disabled peers. Although the majority of young people with disabilities also reported that their parents would disapprove of their actions, in contrast to their non-disabled peers, most of the young people with disabilities said that their parents' views would matter to them.

This research has highlighted the importance of people's unique learning and socialisation experiences in shaping not only their health knowledge, but also their attitudes and beliefs. A number of implications for health education and for professionals working with both individuals with disabilities and their families are outlined. New avenues for research are also suggested.

Declaration

“I hereby declare that I am the sole author of this thesis, except where the assistance of others has been acknowledged.

It has not been submitted in any form for another degree or professional qualification.”

Jaycee D. Pownall

December, 2009

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Chapter 1: Background; Health Challenges Faced By Young Scots

1.1 Introduction

The aim of this thesis is to further our understanding of how social exclusion may impact upon young people with disabilities' health-related knowledge, attitudes and behaviour. The research focuses on data gained from interviewing over 100 young people with and without disabilities. A range of measures, including structured and semi-structured questionnaires and vignette-based methods, were used to elicit information from young people's own perspectives.

This chapter predominately sets the scene for the whole thesis as it provides an overview of the literature relating to understanding adolescent health and behaviour. Outlined is the importance of adopting a life-course perspective in order to tackle health inequalities faced by the Scottish population. Health promotion efforts need to be focused on young people; during adolescence many health behaviours are initiated and habits established, which can continue to influence health and morbidity throughout life (Viner and MacFarlane, 2005). The importance of improving the health of young people is also echoed across Scottish policy documents and some recent policy initiatives relating to adolescent health will be outlined. Finally, this chapter will end by providing an overview of the research on the prevalence of adolescent health behaviours among Scottish adolescents.

1.2 Adolescence and Health-Related Behaviours

Scotland has poor health by both UK and European standards and even though it has improved over the last decade, Scotland has the highest or amongst the highest rates of major diseases of the developed world, such as coronary heart disease, cancer and stroke (Scottish Executive, 2003a). When compared to England and Wales, Scotland's rates of premature death are approximately 30% higher, despite having declined by a sixth over the last decade. For some regions in Scotland (i.e. West Central Scotland) this rate is double that seen in England and

Wales (www.poverty.org.uk). Although higher levels of deprivation have frequently been cited as a cause of these health inequalities, still these inequalities remain even after controlling for levels of deprivation (Hanlon et al., 2001; Hanlon et al., 2005). This has led to the suggestion that there is a yet unidentified "Scottish effect" contributing to Scotland's relatively high mortality rates. Research has investigated the processes underlying these observed health differences, such as our genetic make-up and psychological, behavioural, social and environmental factors (Lang, Dowler and Hunter, 2006) and the mechanisms that mediate these processes.

To understand why people differentially experience health and disease, it is important to adopt a life-course perspective. This perspective focuses on how social determinants of health operate at different developmental stages in an individual's life (i.e. conception, childhood, adolescence), and explores how early life experiences can influence later adult vitality and mortality (Kuh and Smith, 2004). Adolescence is traditionally viewed as a time of optimal health. However, it has also been argued that at no other life stage will an individual have to deal with so many changes, transitions and developmental tasks, nor will these ever occur again at such a rapid rate (Jessor, 1984). Adolescence represents a transition from childhood to adulthood; a transition from immaturity to maturity and dependence to independence. This transition is considered to be continuous and gradual, with the growth and changes spanning many domains. Whilst one important and observable change is the onset of puberty and the growth spurt, transitions are also cognitive, social, and emotional. With regard to cognitive change, as an individual enters adolescence, they are able to deal with more complex topics, i.e. thinking hypothetically, abstractly, using relative thinking and meta-cognition, and begin to think in terms of multiple causes and effects (Cobb, 1998). Social and environmental changes for young people include a greater emphasis on developing more mature relationships with peers and the emergence of sexual and romantic relationships. Emotionally, adolescents strive to establish a sense of autonomy and a sense of identity. Developmental theorists have often discussed risk-taking behaviours in adolescents as being both statistically normative and psychologically adaptive (Parsons, Siegel and Cousins, 1997). It is a period of exploration and experimentation, from which individuals can begin to explore adult-like activities. In this way, risk is purposeful as it helps to establish autonomy from parents and other authority figures,

demonstrates a transition away from childhood and towards adulthood, and helps to develop relationships with peers.

However, greater autonomy also provides individuals with an opportunity to engage in behaviours that may adversely affect health. Adolescence is also a period when a significant proportion of mortality and morbidity rates can be attributed to the behavioural decisions of the young person (Rodham, Brewer et al., 2006), with adolescents being over represented on almost every type of health risking behaviour (Kuther and Higgins-D'Alessandro, 2000). There is also ample evidence that positive health behaviours (such as healthy eating and physical exercise) and health risk behaviours (such as unsafe sex practices and alcohol use) initiated in adolescence are continued into adulthood (Jessor, 1984; Viner and McFarlane, 2005). In addition, there have been major social changes over the last few decades which have implications for young people and health. The period of 'youth' is becoming lengthier; puberty is beginning earlier as is the onset of sexual relations, marriage and entry into the labour market is being delayed as more individuals spend longer time in education and training (Furlong, 2002). As a consequence, the transitions that we would have normally associated with 'adult status' or independence have become less structured (Coleman et al., 2007b). It has been argued that this longer period of transition contributes to emotional stress and greater uncertainty about the future (Coleman et al., 2007b; Furlong, 2002).

Marginalised groups and vulnerable young people have additional needs and often experience many of the poorest health outcomes, and as such may need added support. The specific health inequalities experienced by people with intellectual disabilities have been widely documented, demonstrating increased mortality rates compared to the general population (NHS Health Scotland, 2004; Horwitz et al., 2000; Ouellette-Kuntz et al., 2004). Socio-economic position is also important, with male life expectancy in the most deprived areas in Scotland being more than 13 years lower than in the least deprived areas (this being 8.6 years for females). Moreover, the gap between the most and least deprived appears to have widened in the recent past (data from 2004–2006; Scottish Government, 2008).

Therefore, developing a better understanding of the influences on adolescent behavioural choices may also help in our endeavour to promote healthier lifestyles which will continue

into adulthood. This long-term strategy for tackling health inequalities can be seen in Scottish policy documents, such as *Improving Health in Scotland; The Challenge* (Scottish Executive, 2003), *Building a Better Scotland* (Scottish Executive, 2004a) and *Closing the Opportunity Gap* (Scottish Executive, 2004b).

A core principle underpinning all these policy documents is the need to begin working with children and young people to give them the best possible start in life.

1.3 Healthy Eating, Alcohol Use and Sexual Health

This section will be divided into three sections: eating habits, alcohol use and sexual health. The aim of this section is to provide an overview of the research regarding recent trends and the prevalence of behaviours in relation to each of these areas. The main focus will be on young people in Scotland, however where appropriate and where data is available, comparisons will be made with the rest of the UK and abroad. Data will be presented for typically developing young people first, followed by young people with intellectual and physical disabilities. Data will be gathered from a range of sources, with the bulk being drawn from health surveys carried out in the Scotland, the rest of the UK and, where appropriate, Europe. An overview of the surveys consulted is provided in appendix A.

It is important to note that when approaching adolescent health, particular issues cannot and should not be addressed in isolation. In attempting to improve the health of young people, we need to go beyond the individual to include the complex interactions between biological, psychological and social factors. This chapter therefore serves to highlight the health issues and provides a backdrop for subsequent chapters, which try to build a more complete picture.

1.3.1 Healthy Eating

1.3.1.1 Dietary Intakes in Adults with and without Disabilities

In July 1996, *Eating for Health: A Diet Action Plan for Scotland* (Scottish Office, 1996), known as the Scottish Diet Action Plan (SDAP) was published by the Scottish government, setting out a series of targets for dietary improvements for the year 2005.

In 2006, Health Scotland published a review of the implementation of the SDAP between 1996 and 2005 (Lang et al., 2006). This report reviews the progress made in implementing the SDAP recommendations and achieving targets. In addition, the Food Standards Agency Scotland commissioned a review of national dietary and health surveys, comparing current information on the Scottish diet with these targets (Wrieden et al., 2006). Comparing the dietary targets outlined in the SDAP with data from the National Food Survey (NFS) and the Expenditure and Food Survey (EFS) data collected in 1996 and 2004, respectively, overall the report found that the targets would not be met in 2005. Scots were falling considerably short of the target for fruit and vegetable consumption, bread, breakfast cereal and fish consumption, and were consuming too high a level of non-milk extrinsic (NME) sugars. Although the amount of fat as a total percentage of food energy had decreased slightly, this was still higher than the recommended level.

Despite the increased prevalence of overweight and obesity in adults and children with disabilities (Humphries et al., 2009; Melville et al., 2006), detailed information on dietary intakes is not available, or at least to the same extent as it is for the general population. This is partly due to the frequent exclusion of these individuals from large-scale health surveys. Whilst it is important to assess food habits and lifestyle to provide a more comprehensive picture of an individual's nutritional adequacy, it is also important to acknowledge that obesity results from multiple interactions between genes and environment, including factors like early experiences with food, family food choices, levels of physical activity and sedentary behaviour (Maffeis, 2000). For people with disabilities the factors influencing obesity would appear more complex than for the general population. Consideration needs to be given to physiologic or metabolic differences, altered body composition and nutritional needs,

influences of medication, along with social and psychological matters such as financial restraints, lack of support and poor knowledge (Humphries et al., 2009; Rimmer et al., 2007).

Several studies have attempted to explore the dietary intakes of adults with intellectual disabilities (Bertoli et al., 2006; Braunschweig et al., 2004; Cunningham et al., 1990; Draheim, Williams and McCubbin, 2002; Lindeman, 1991; McGuire, Daly and Smyth, 2007; Robertson, Emerson et al., 2000). Table 1.1 summarises the key findings of these studies. Overall, these studies suggest that adults with intellectual disabilities often have nutritionally poor diets which tend to be high in fats, sugars and junk food, yet are low in fruit, vegetables, fibre and dairy products. As with the general population, adults with intellectual disabilities are not consuming the recommended targets for fruit and vegetable or starchy carbohydrates, with an excessive consumption of simple carbohydrates (i.e. sugary foods and drinks). A similar pattern has also been reported for adults with physical disabilities; Bertoli et al. (2006) reported that although people with physical disabilities had intakes that compared favourably to people without disabilities, their diets were still too high in saturated fats, simple carbohydrates and protein and too low in complex carbohydrates and fibre. Poor diet accompanied by low amounts of physical activity and reduced muscle mass, may help to account for the increased prevalence of obesity in these individuals. In addition, intakes of micronutrients, such as calcium, potassium, iron and zinc have been reported to be lower for individuals with physical or intellectual disabilities (Bertoli et al., 2006). Low calcium intake is a particular concern, as if this is accompanied by reduced daily physical activity the individual may be at increased risk of developing osteopenia and osteoporosis (Bertoli et al., 2006).

However it is difficult to make any firm conclusions about the dietary intake of adults with intellectual and physical disabilities, owing to the different dietary intake methods employed across studies (e.g. 7-day food record, Bertoli et al., 2006; Braunschweig et al., 2004; 4-day food, semi-weighed record, Cunningham et al., 1990; menu review, Lindeman, 1991; and food frequency questionnaires, Braunschweig et al., 2004; Draheim et al., 2002; McGuire et al., 2007; Robertson et al., 2000). Few studies have attempted to access information directly from the participant, and as such food consumed away from the family member/carer completing the measure may not be recorded. There are many challenges to accurately

measuring diet, and these may be less reliable for people with intellectual disabilities, particularly if measures rely on memory recall of what was consumed (e.g., 24-hr recall or food frequency records). Socioeconomic, religious and ethnic factors also need to be recognised when trying to draw comparisons across studies, as these all influence an individual's nutritional attitudes and practices. Moreover, differences in the study sample populations in terms of size, level of ability, and residential settings mean any comparisons and generalisations should be made tentatively (Robertson et al., 2000; Rimmer, Braddock and Marks, 1995).

1.3.1.2 Dietary Intakes in Young People without Disabilities

Data specific to young peoples' dietary habits from the general population will be drawn from two main sources: the National Diet and Nutrition Survey (NDNS; Gregory et al., 2000) and the Scottish Health Survey for children (SHS; Bromley et al., 2005). It should be emphasised again that differences in methods does not allow direct comparisons across surveys. For example, the NDNS uses a seven-day weighed intake dietary record of foods consumed in and out of the home, giving detailed numerical data on food and nutrient intake. However, the participants may under report their dietary intake due to the complexity of the monitoring system and the level of commitment required by the participants. Conversely, the Scottish Health Survey used 24-hour recall of food intake and only covers select foods. With the exception of fruit and vegetables, the SHS only provides data on frequency of food consumption, not quantities. In addition the latest NDNS reports data collected in 1997, whereas the SHS was 2003. Therefore, the two surveys will be used to give a fuller picture of young peoples' diets in Scotland, but comparisons should be made cautiously.

Fruit and Vegetable Consumption

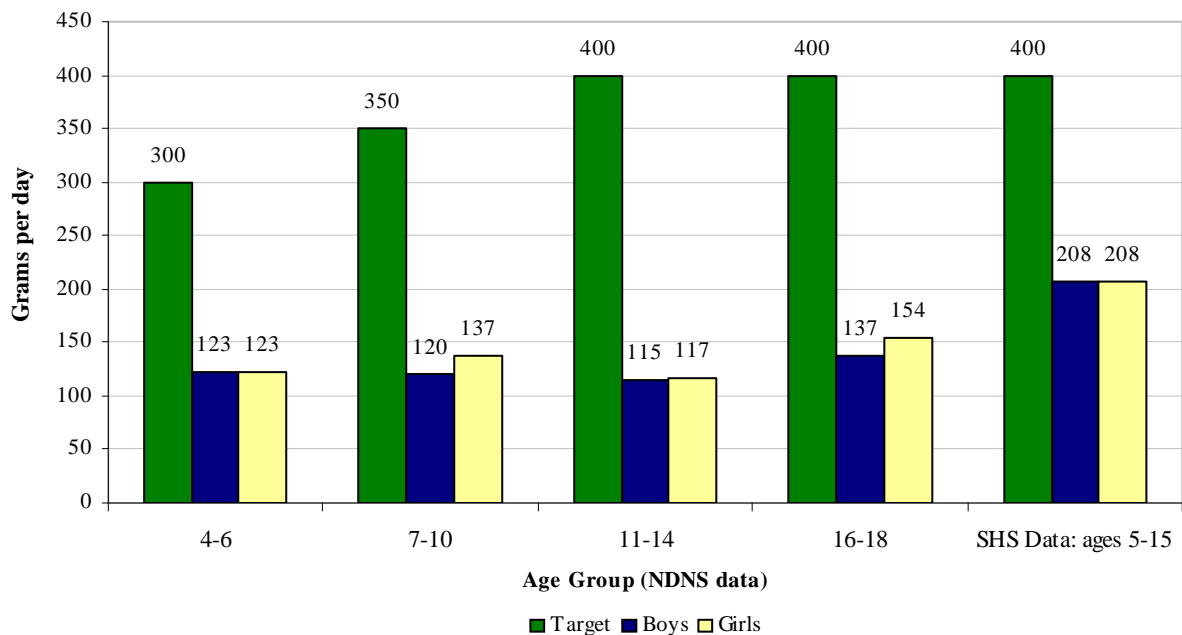
Increasing the intake of fruit and vegetables was cited as being the most important target in the SDAP. The recommended target for 2005 was that the average intake of fruit and vegetables should increase to more than 400g a day, equivalent to the World Health Organisations' recommended daily consumption of five portions of fruit and vegetables (World Health Organization, 1990). Looking specifically at young people across Britain, data from the National Diet and Nutrition Survey (NDNS, 2000) reported that young people across all ages

Table 1.1: Key Findings of Dietary Intake Studies

Study & Sample Characteristics	Fruit & Vegetable	Fat	Carbohydrates	Fibre	Dairy	Protein
Bertoli et al. (2006) 37 Italian adults residing in community settings, age range 17-54 , PD = 24, ID/PD = 13, ND = 25	-----	Energy from fat : PD-29.4%; ID/PD -35%; ND-32.2% Grams/day saturated fat: PD-19.4; ID/PD-24.2; ND - 35.5 g/day	Energy from carbs: PD-50.3%; ID/PD-47.7%; ND-52.4%	PD-13.4; ID/PD-13.7 ND - 22.6 g/day	-----	Energy from protein: PD-15.3%; ID/PD-16.3% ND-13.4%
Braunschweig et al. (2004) 48 US community-dwelling adults with Down's Syndrome, mean age 39.6	None consumed five p/day Fruit 2.8 p/day Veg. 1.0 p/day	29% energy from fat 10% energy from saturates	54% of total energy	18 g/day	-----	Average 6.1 meat servings day 18% of total energy.
Cunningham et al. (1990) 332 Irish adults in long-stay institutions with moderate/profound ID, age range 15-64	-----	Males 119 g/day, females 90.6 g/day 43% of energy from fat	Males 240.6 g/day Females 204.6 g/day Energy from simple carbs: 33%	Males 20.2 g/day Females 17.4 g/day	-----	Males 107.3 g/day Females 86g/day
Draheim et al. (2002) 145 US adults, age range 18-65, DS n=75, ID n=70 residing in community settings	<37% consumed five p/day	92% obtained >30% energy from fat 64% >35% energy from fat	-----	-----	-----	-----
McGuire et al. (2007) 157 UK adults aged 16-65 living in residential & family setting Compared to national sample	42.4% four p/day (ND 72%) Average 3.6 p/day (range 0 – 12)	70% <three servings fats/sugar p/day (considered ideal; ND 17%) 1.2% Fried foods >4/wk (ND 9.2%)	25.9% 'ideal' six p/day (ND 34%) Average 4.76 p/day (range 0.57 -13.86)	-----	9.5% 'ideal' three p/day (ND 33%) Average 1.64 p/day	17% two portions/day (ND 38%) Average 1.34 p/day (range 0.29 to 9)
Robertson et al. (2000) 481 UK adults aged 18 +, Various, non-institutional residences	19% four p/day ((range 16%-44%))	-----	43% 'ideal' four p/day (range 41%-45%)	-----	79% two portions milk/milk based foods a day (range 70%-87%)	72% two portions/day (range 69%-75%)
Lindeman (1991) 61 US adults aged 19-58, living in group homes, assessed intake via menu review	-----	Energy from fat : 42% Energy from sugars : 24%	Energy from carbohydrate : 42%	Energy from fibre : 12.4g p/day	-----	Energy from protein : 16%

fell significantly short of meeting the targets in 1997 (figure 1.1). Reported fruit and vegetable consumption was slightly higher in the Scottish Health Survey (SHS), with mean fruit and vegetable consumption in the previous 24 hours being 2.6 portions (208 grams; figure 1.1); however, this still remained well below the target. In fact, 12% of boys and girls reported eating no fruit or vegetables in the previous 24 hours, and only 12% reported consuming more than five portions a day. The Scottish Health Survey compared its findings with the Health Survey for England, noting little differences in fruit and vegetable consumption, with one exception; girls in Scotland were more likely than their English counterparts to state they ate no fruit or vegetables (12% versus 8%). Young people aged 16-24 years are the least likely to meet the recommendation than any other (older) group. The Health Behaviour of School Children (HBSC; Currie et al., 2004) study compared internationally young peoples' frequency of consuming fruit and vegetables on a daily basis. Across the 35 countries and regions surveyed Scotland, England, and Wales ranked approximately 15th, 28th and 30th, respectively for fruit consumption (with 35th being lowest number consuming fruit daily) and 16th, 25th and 31st respectively, for vegetable consumption.

Figure 1.1: Consumption of Fruit and Vegetables by sex and age: Results from the National Diet and Nutrition Survey 1997 and the Scottish Health Survey, 2005



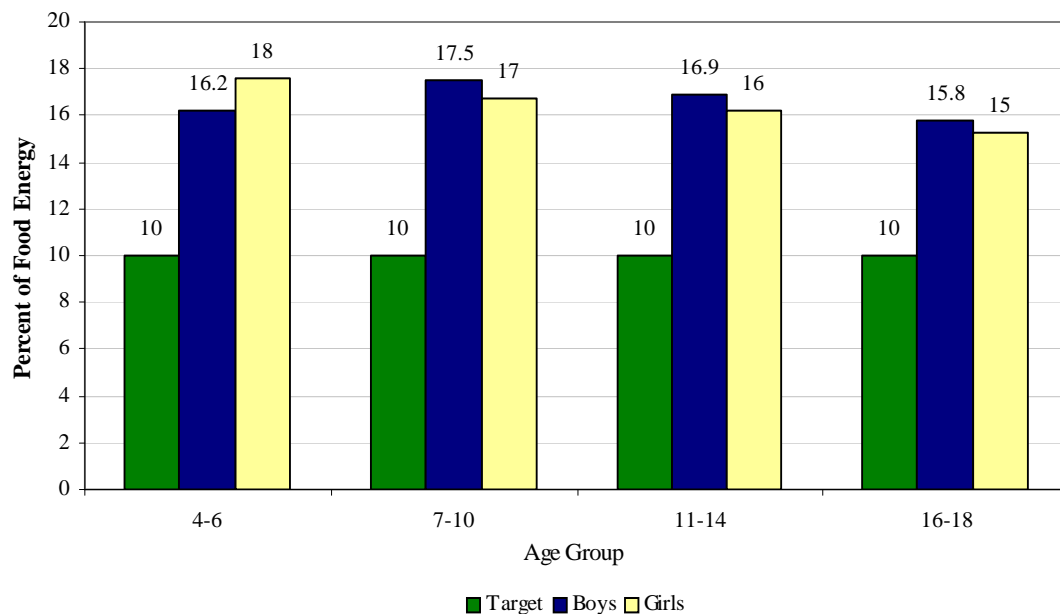
Sources: Gregory et al. (2000) *National Diet and Nutrition Survey: Young People Aged 4 to 18 Years, volume 1: report of the Diet and Nutrition Survey*, London: TSO

The Scottish Executive (2005) *The Scottish Health Survey 2003, volume 3: children*. The Stationery Office: Edinburgh

Sugary Foods and Snacks

Reducing intake of non-milk extrinsic sugars (NME) was the only target set specifically for children in the SDAP (<10% of total energy). In 1997, sugar intake formed 16.7% of boys' aged 4 to 18 food energy and 16.4% of girls (NDNS, 2000; figure 1.2). Therefore, children as young as four were consuming well beyond the current recommended levels with regard to NME sugar consumption, implicated in the aetiology of dental cavities. The Scottish Health Survey revealed that a large proportion of young people aged 5-15 years consume sweets, chocolates and sugary drinks on a daily basis. Fifty-seven percent of boys reported eating sweets and chocolates once a day or more, as did 60% of girls, and 46% of boys and 43% of girls reported consuming sugary drinks at least once a day. International comparisons showed that Scotland has one of the highest percentages of daily consumers of sweets and chocolates and sugary drinks.

Figure 1.2: Consumption of Non-Milk Extrinsic Sugars (NME) Sugars by sex and age: Results from the National Diet and Nutrition Survey 1997

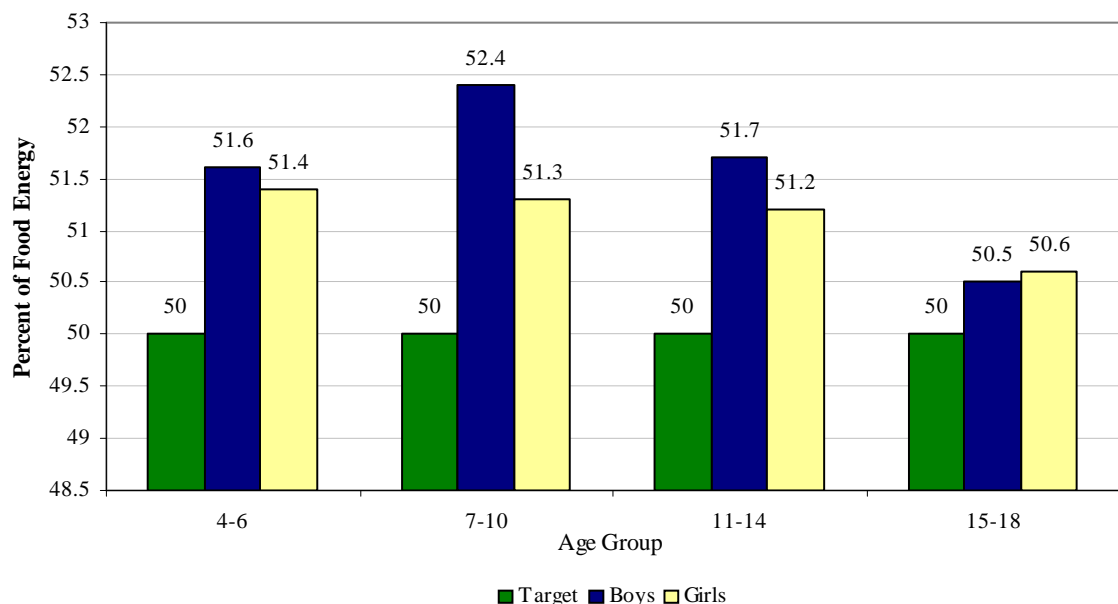


Sources: Gregory et al. (2000) *National Diet and Nutrition Survey: Young People Aged 4 to 18 Years, volume 1: report of the Diet and Nutrition Survey*, London: TSO

Starchy Carbohydrates and Dietary Fibre

The NDNS reported that total carbohydrates made up 51.6% and 51.1% of total energy for boys and girls respectively (figure 1.3), which slightly above the recommended amount (48.5% for males and 47.7% for females; British Nutrition Foundation, 2004), although a substantial proportion of this was coming from NME sugars (see above). The SHS reported that 77% of boys and 73% of girls said they consumed 2-3 slices of any bread a day and this increased with age. Seventy-four percent of boys and 65% of girls ate breakfast cereals 5-6 times a week or more, and 48% of boys and 51% of girls stated that they consumed potatoes, rice or pasta at least five times a week. However this only provides broad information about dietary intakes, and does not give information as to whether young people are actually meeting the targets.

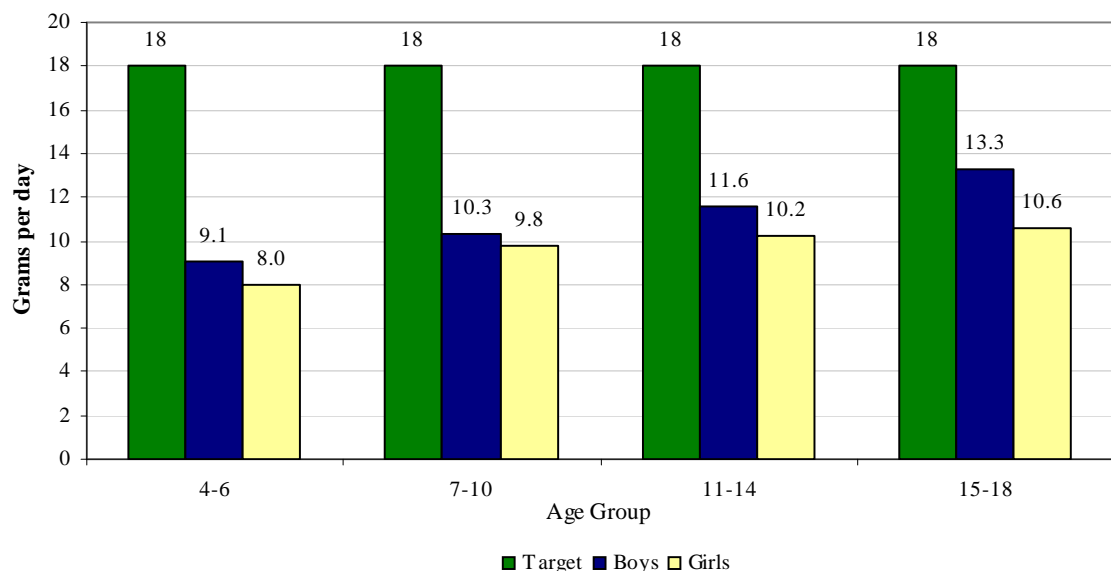
Figure 1.3: Consumption of Carbohydrates by sex and age: Results from the National Diet and Nutrition Survey 1997



Sources: Gregory et al. (2000) *National Diet and Nutrition Survey: Young People Aged 4 to 18 Years, volume 1: report of the Diet and Nutrition Survey*, London: TSO

The Scottish Dietary Targets also advocate increased fibre in the diet. Although there are no specific recommendations for fibre intake (referred to as non-starch polysaccharide fibre) in children, it should be proportionate to body weight; for adults the target is 18g/day. According to the NDNS, boys in Britain were consuming approximately 11.2 g/day and girls 9.7 g/day (figure 1.4). Although 75% of children reported in the SHS reported consuming 2-3 slices of any bread a day, of these only 16% of boys and 13% of girls reported consuming high fibre bread. Similarly 69.5% of girls ate breakfast cereals 5-6 times a week or more, only 27% of boys and 22% of girls ate high fibre cereals.

Figure 1.4: Consumption of non-starch polysaccharide fibre by sex and age: Results from the National Diet and Nutrition Survey 1997



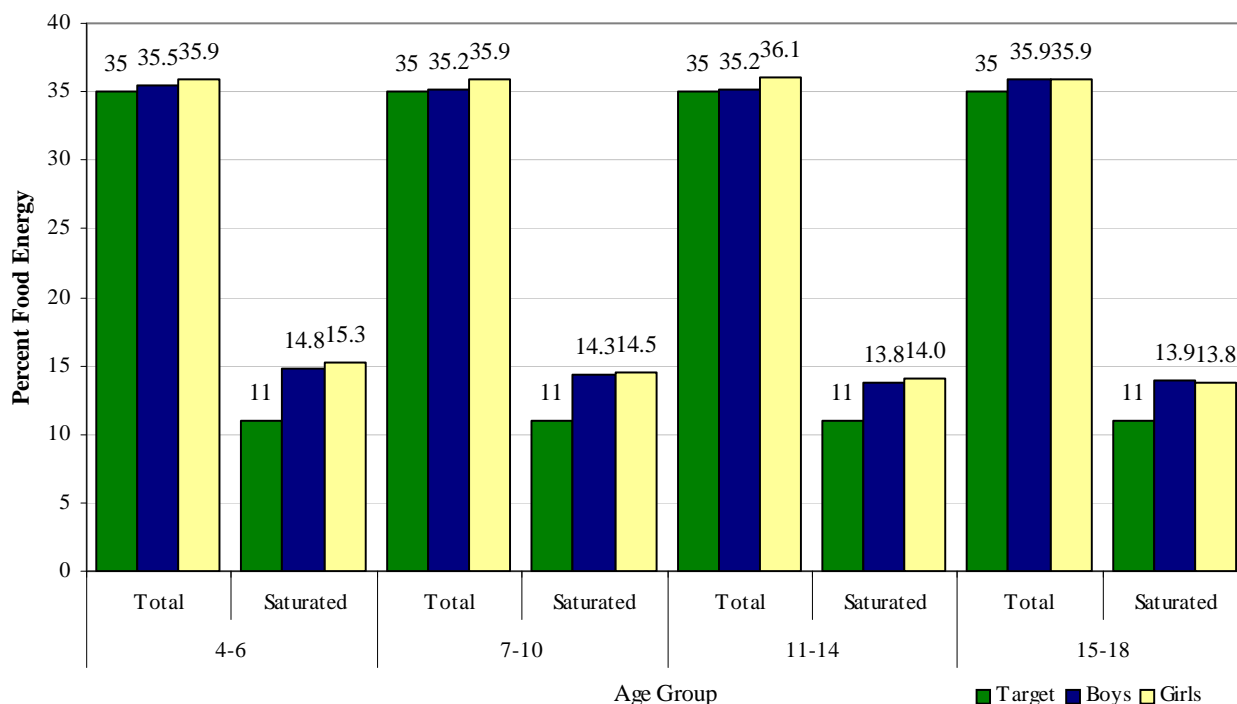
Sources: Gregory et al. (2000) *National Diet and Nutrition Survey: Young People Aged 4 to 18 Years, volume 1: report of the Diet and Nutrition Survey*, London: TSO

Total Fat and Energy Dense Foods

According to the NDNS, for boys fat made up 35.4% of food energy intake and for girls this was 35.9% (target 35%). However, just over 14% of this came from saturated fat, recommended to make up no more than 11% of energy intake (figure 1.5). Sources of fat and saturated fat for young people were mainly biscuits, buns, pastries and cakes and meat and meat products, but also included savoury snacks and milk and milk products. According to the

SHS, energy dense foods such as cakes, scones, sweet pies, pastries, were consumed once or more a day by 51% of boys 45% of girls.

Figure 1.5: Consumption of total fat and saturated fats by sex and age: Results from the National Diet and Nutrition Survey 1997



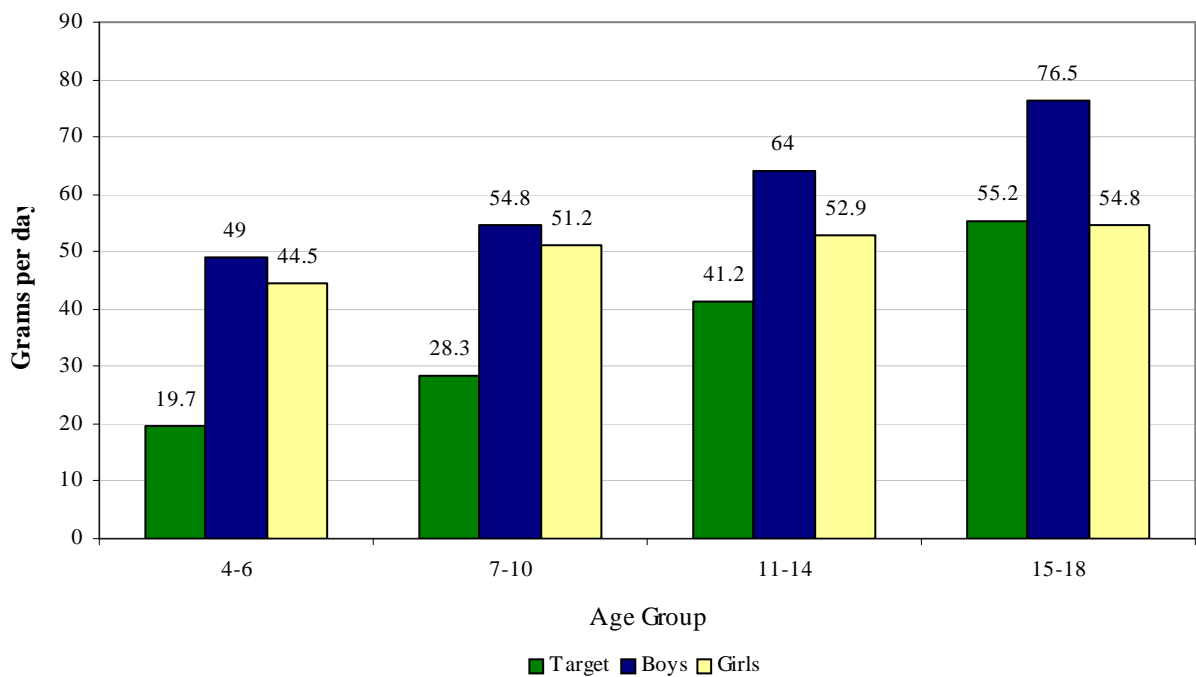
Sources: Gregory et al. (2000) *National Diet and Nutrition Survey: Young People Aged 4 to 18 Years, volume 1: report of the Diet and Nutrition Survey*, London: TSO

Meat and Fish

With regard to protein intake in children, although this increases with age, the average amount is recommended to be 36 g/day. Average protein intake according to the NDNS was actually higher than this (61.6% for boys and 51.2% for girls; figure 1.6), the main sources being meat and meat products. Fifty-five percent of boys in the SHS reported consuming red meat at least twice a week, as did 52% of girls. This was highest in boys aged 14-15 years, but lowest in girls of this age range. With regards to poultry, 68% of boys and 70% of girls reported eating it at least twice a week. The specific dietary targets for fish consumption are 107g/week of white fish and 88g/week of oily fish. Although this information is not provided on how many portions this is, it can be taken to roughly mean at least two or three portions of fish per week,

one portion of which should be oily. In the SHS 45% of boys and 39% of girls were eating white fish at least once a week, but only 8% of children consumed oily fish at least once a week.

Figure 1.6: Consumption of protein by sex and age: Results from the National Diet and Nutrition Survey 1997



Sources: Gregory et al. (2000) *National Diet and Nutrition Survey: Young People Aged 4 to 18 Years, volume 1: report of the Diet and Nutrition Survey*, London: TSO

Although the findings presented should be interpreted with caution due to differences in data collection methods, it does appear that young people in Scotland, along with their adult counterparts, are still a long way from reaching the dietary targets set out in the 1996 SDAP. For some food groups, like protein, it would appear that young people are meeting or close to meeting recommended amounts. However, it is clear that protein still tends to be eaten as part of an unhealthy diet, including meat composites in pies or curries. Thus, the diet of the Scottish population is still likely to be adversely affecting their health.

1.3.1.3 Dietary Intakes in Young People with Disabilities

There are very few studies that have explored dietary behaviours of young people with intellectual and physical disabilities, despite the fact that the onset of obesity is earlier in adults with intellectual disabilities than in the general population (Melville et al., 2007). This finding highlights the need to explore possible contributing factors to obesity that may occur during adolescence or earlier for this population (Melville et al., 2007).

Medlen and Peterson (2000) conducted a postal survey with teens and adults with Down's syndrome (aged 15 to 45 years) regarding their dietary and exercise behaviour. They found that almost everyone ate breakfast, lunch, and dinner, and over 50% of those meals were considered 'balanced'; that is they included at least three of bread, fruit, vegetable, milk, or meat. However, over 50% of the sample had between-meal snacks, of which only 20–32% were considered balanced and tended to be high in calories and low in nutrition. On average participants were eating five to six times each day or more, suggesting that they were consuming more calories than were required. Jobling and Cuskelly (2006) asked a group of 38 young people with Down's syndrome about their favourite foods. Fifty-eight percent of the participants chose foods that were high in sugar and fats; of these individuals 81% stated they ate these foods everyday. Forty-eight percent of the sample also ate foods that were high in sugar and fats for lunch.

Luke, Sutton et al. (1996) explored energy and nutrient intakes of ten prepubescent children (aged between 5 and 11 years) with Down's syndrome living in the US. Dietary intakes were recorded for 3 consecutive days by a parent of the participant. With regards to energy intakes, young people with Down's syndrome had a significantly lower energy intake when expressed as a percentage of recommended amount compared to non-disabled controls ($n=10$; 86.5% versus 111.3%). For example, carbohydrates formed 53% of total energy intake for young people with Down's syndrome and 50.9% in the control groups (recommended intake 50 to 55%), although young people with Down's syndrome consumed less high-sugar snacks (simple carbohydrates). Fat and protein intakes formed 30% and 17.4% of the Down's syndrome group's total energy intake, respectively, compared to 33.3% and 16.9% in the control group. However, both groups failed to consume the recommended amount of fruit and

vegetables or dietary fibre intake per day. Participants with Down's syndrome had lower intakes of several vitamins and minerals, including calcium, which put them at risk for vitamin or mineral deficiencies. In addition, this study found that participants with Down's syndrome had a 10% to 15% lower resting metabolic rate compared to the control group, putting them at greater risk for developing obesity. Although this study was promising with regards to a healthy diet in young people with Down's syndrome, with the exception of fibre and fruit and vegetables, it should be born in mind that the sample size was very small and this study was conducted in the US. Therefore, although studies examining the prevalence of overweight and obesity in young people with intellectual disabilities are increasing and have highlighted this as an area of concern, few studies have explored dietary intakes and how these influence risk for developing overweight or obesity.

Steele et al. (2004) used data from the Canadian version of the Health Behavior in School-Aged Children (HBSC) Survey to compare age related health risk behaviours (including alcohol use, physical and sedentary activity, and dietary habits) in young people with and without physical disabilities. Three-hundred and nineteen adolescents aged from 11 to 16 years with a moderate to severe physical disability and 7,020 adolescents without a disability took part in the study. Across the different age groups, adolescents with physical disabilities were less likely to consume fresh produce than their non-disabled peers (consuming fruit and vegetables less than once a day: 70-77% versus 57-60%) and were more likely to consume high fat foods (26-37% versus 20-26%). However, adolescents with physical disabilities were less likely to consume sweets, chocolate, or soft drinks once a day or more than their non-disabled peers (54-66% versus 77-84%). Hogan, McLellan and Bauman (2000) reported that 11 to 16 year olds with a range of disabilities consumed fast food more frequently than participants without disabilities.

Therefore there is some evidence that young people with physical disabilities may have poorer diets than their non-disabled peers. However, there are an array of additional factors that need to be considered when examining dietary behaviours and young people with physical disabilities. Anderson (1993) discusses how some children with disabilities are placed on special diets where food may be pureed and lack fibre, whereas allergies and metabolic disorders may mean some foods are removed from the diet altogether. Feeding difficulties

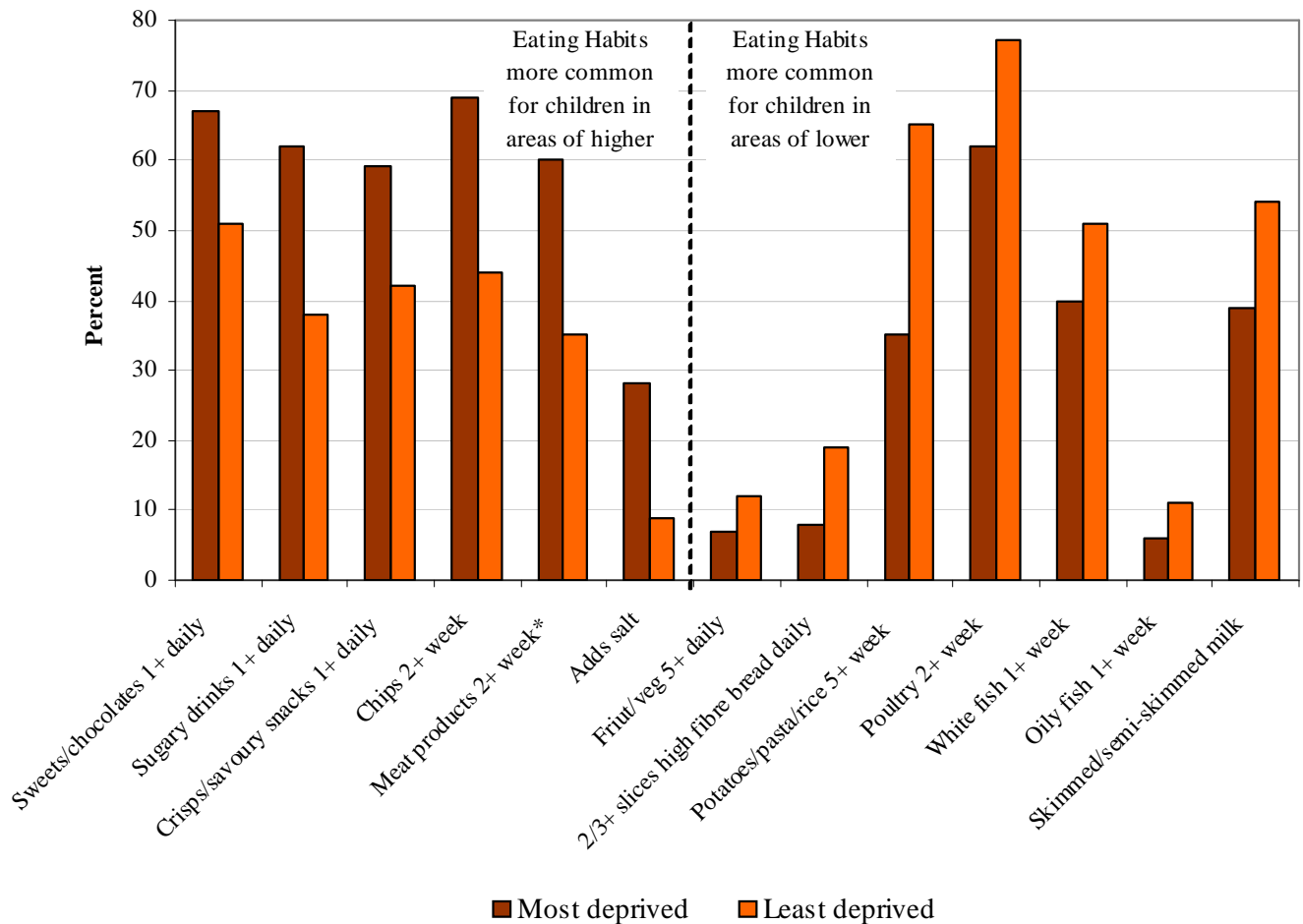
experienced by some participants need to be considered, including refusal to eat from specific food groups, eating a limited variety of foods, difficulties in using eating utensils, and failure to chew food properly (Calvet et al., 1976). Children with severe disabilities are more likely to have oral motor dysfunction (necessitating increased time for meals), poor feeding skills, food refusal, coughing, aspiration, reflux, and vomiting. Together this could create a negative energy balance and under nourishment (Stallings et al., 1996). It has been argued that fresh produce is harder to chew and swallow, whereas foods that are high in fat (i.e. chips) are easier to eat (Steele et al., 2004). The need to get young children to eat *something* may overwrite the importance of healthy eating although such habits may be harder to undo later in life (Minihan, Fitch, and Must, 2007). Food may also be used to reinforce desired behaviours, which then lead to poor eating habits (Minihan et al., 2007). In addition, the health care needs of their child causes financial restraints on parents and therefore fewer resources can be spent on making healthy meals or on adaptive equipment for physical activity (Minihan et al., 2007).

Another important factor involved in the genesis of obesity is physical activity; there is evidence that individuals with intellectual and physical disabilities are less likely to engage in physically active lifestyles than people without disabilities (Heath and Fentem, 1997; Jobling and Cuskelly, 2006; Jones and Bell, 2004; Liou et al., 2005; Rimmer and Braddock, 2002; Rurangirwa, Van Naarden Braun et al., 2006). Barriers to participation in physical activity may include i) structural barriers such as inaccessible access routes, narrow doorways, ii) cost and economic factors, including lack of adaptive or accessible equipment, iii) lack of knowledge and negative perceptions and attitudes towards people with disabilities exercising, and iv) lack of resources such as transportation (Rimmer, Riley et al., 2004). In addition, fatigue may be another reason that people with disabilities have less healthy lifestyles (Becker and Stuifbergen, 2004). For example, being too tired to cook is often stated as a reason for poorer diets in this population (Hall, Colantonio, and Yoshida, 2003).

Data has not been reported here on the association of deprivation with eating habits, although this is available in surveys from the general population. In general, the SDAP targets are the least likely to be achieved in the most deprived areas (figure 1.7). Healthy habits such as eating five portions of fruit and vegetables a day, eating high fibre foods, starchy

carbohydrates, white meat, fish and low fat versions of milk are all more common in areas with lower rates of deprivation. Conversely, eating sweets and chocolates, sugary drinks and snacks, chips, meat products and salt are more common habits for young people in areas of high deprivation (Bromley et al., 2005).

Figure 1.7: Eating Habits in high and low deprivation areas



Source: The Scottish Executive (2005) *The Scottish Health Survey 2003, volume 3: children*. The Stationery Office: Edinburgh

1.3.2 Alcohol Behaviour

1.3.2.1 Alcohol Consumption and Young People without Disabilities

The Scottish Executive has identified tackling alcohol misuse as a priority in Scotland, highlighted through the publication of the *Plan for Action on Alcohol Problems* in 2002 (Scottish Executive, 2002a). *The Plan for Action on Alcohol Problems*, whilst acknowledging the positive aspects of alcohol use (relaxation, health benefits of moderate use, and benefits to tourist industry), also emphasises the serious consequences that excessive drinking can have. Short-term health effects of excessive drinking include intoxication and its associated risks; long-term health effects may involve liver damage, damage to the cardiovascular, nervous and gastrointestinal systems, and can impact upon mental health. In 2004 there were over 2,052 alcohol related deaths, an increase of 21% over the last five years (Information Services Division, ISD Scotland, 2005). The ratio for alcohol related death for men and women is 3:1, respectively (ISD Scotland, 2005). There was also an increasing trend in the rate of emergency admissions due to acute intoxication and harmful use of alcohol. Although emergency admissions were the highest for males and females in the 45-64 age range (89.6 and 25.6 per 10,000 in 2003/4 for males and females, respectively), young people aged 16-25 formed a substantial proportion of these figures (47.1 per 10,000 males and 19.4 per 10,000 females, respectively).

At a societal level excessive alcohol use is associated with violence, drink driving, crime, family and financial difficulties and social exclusion (NHS Scotland, 2005). The estimated annual cost of alcohol misuse to Scottish society is £1070.6m (Scottish Executive, 2002b). Thus, the situation in Scotland relating to alcohol is a serious one. During adolescence however there are unique health and social risks associated with alcohol use because of the stage in development and the fact that children and young people's bodies have a lower capacity to process alcohol (Newburn and Shiner, 2001). In addition, habits that are initiated in youth may be maintained later on in life (Viner and McFarlane, 2005) leading to greater harm both to the individual and society. The remainder of this section will focus on the research examining alcohol related behaviour in children and young people.

Prevalence of alcohol consumption in young people has been measured since the 1970s, usually with local and regional studies of drinking behaviour. In addition, there are several health surveys that include questions about young peoples' alcohol related knowledge, attitudes and behaviour. This section draws mainly on the following surveys, with details provided in appendix A:

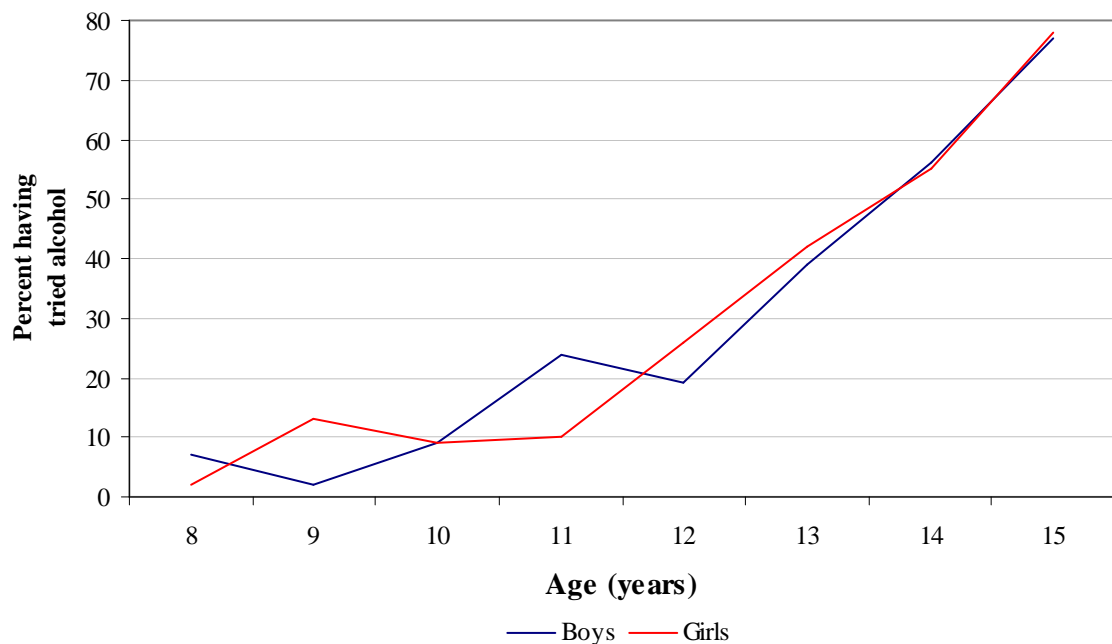
- The Scottish Health Survey (**SHS**) for 2003 (Bromley et al., 2005)
- The Scottish Schools Adolescent Lifestyle and Substance Use Survey (**SALSUS**) for 2004 (Corbett et al., 2005).
- Wright, L. (1999) *Young People and Alcohol: What 11 to 24 Year Olds Know, Think and Do*. London: Health Education Authority
- The Health Behaviours School-aged children (**HBSC**) study, which includes data on alcohol use in Scotland in the 1990s (Todd, Currie and Smith, 1999) and data from 35 different countries and regions in 2001/02 (Currie. et al., 2004).

In reviewing the literature on alcohol use and young people in England, Wright (1999) states that drinking usually begins at 8-12 years of age, with virtually all 12-14 year olds having had some experience of drinking. Young people's drinking appears to gradually increase up to the age of 10 or 11 years of age, after which experience is rapidly gained up to the age of 15 years (figure 1.8; Bromley et al., 2005). For example the Scottish Health Survey (SHS) reported that at the age of 8, only 7% of boys and 2% of girls reported having tasted alcohol. By the age of 15, this had risen to 77% of boys and 78% of girls in the SHS and 86% of boys and 90% of girls in the SALSUS survey (in both surveys, this was defined as '*a whole drink, not just a sip*'). At the age of 16 years, virtually all adolescents (94%) throughout the UK have had some experience of drinking alcohol (Miller and Plant, 1996, cited in Wright, 1999).

Drinking patterns also change with age, reflecting young people's transition into adulthood. For example, young teenagers may begin to experiment with alcohol such as having the 'the occasional sip' of alcohol, but this is predominately within the safety of the family

environment (Newburn and Shiner, 2001) and reflects a “normal part of socialisation within the home” (Wright, 1999. p. 15). However, by the mid-teens drinking begins to resemble that of adult behaviour, with young people drinking independently and away from parental supervision (SHS, 2005; Wright, 1999). There is evidence to suggest that this move toward independent and unsupervised drinking may be associated with increased levels of intoxication (Goddard and Higgins, 2000; SALSUS, 2005). For example, individuals who reported having been drunk previously were more likely to report that they usually drank in public places such as parks and in streets than those who not been drunk, who in turn reported drinking more at home (SALSUS, 2005).

Figure 1.8: Experience of Alcohol by Age and Sex



Source: *The Scottish Executive (2005) The Scottish Health Survey 2003, volume 3: children. The Stationery Office: Edinburgh*

It is important to note that there have often been discrepancies between survey findings, which may reflect the varying methods employed. For example, the Health Behaviour of Scottish Schoolchildren survey (HBSC) reported at the age of fifteen, 98% of individuals had tried alcohol, which was higher than reported elsewhere. Children in both the Scottish Health and

SALUS surveys were asked if they had ever tried alcohol, '*a whole drink, not just a sip*', participants in the HBSC survey were simply asked "have you ever tasted an alcoholic drink". Consequently, it is not necessarily surprising that the latter survey was likely to find that a higher proportion of young people have tried alcohol. In addition, whereas the Scottish Health Survey was conducted in the child's home, the SALUS interview took place in the individual's school. As the authors acknowledged, when children were surveyed at home they may have been concerned that their parents could have discovered their answers and deliberately under-reported their drinking experiences. It is therefore important to keep in mind the wording, design and administration of different surveys, as these methodological factors are likely to influence the findings.

The international report from the HBSC survey examined alcohol-related behaviours across 35 countries and regions (Currie et al., 2004). The average age of drinking onset was 12.3 years for boys and 12.9 years for girls. The differences across the UK were minimal; Wales ranked approximately 6th highest out of the 35 countries for average age of drinking onset (1st being the country in which the average age of drinking onset was the youngest), England ranked 11th and Scotland ranked 12th. Similarly, the Scottish Health survey found that rates of ever having tried alcohol to be higher in England than those in Scotland; 45% of boys and 40% of girls aged 8-15 years in England reported having ever tried alcohol compared to 29% of boys and 30% of girls in Scotland.

With age, there is also a rapid increase in drinking frequency. At 8 years of age, only 1% of boys and 2% of girls reported drinking a few times a year in the Scottish Health Survey, but this rose to 70% and 71% for 15 year old boys and girls, respectively. Furthermore, at 15 years of age, 41% of boys and 29% of girls reported drinking once a month or more, and 15% of boys and 10% of girls drank weekly. The HBSC study found higher rates, with 44% of 15-year-old boys and 45% of 15-year-old girls reporting drinking at least weekly. The international report from the HBSC survey found a higher percentage of young people living in England, Wales and Scotland reported drinking alcohol regularly (defined as drinking any alcoholic drink weekly). For example, whereas on average, 29% of 15 year olds reported drinking regularly, this figure was 52%, 56% and 43% in England, Wales and Scotland, respectively.

There is also some evidence that the proportion of young people drinking in the UK has been steadily increasing over time. The SALUS survey reported that from 1990 to 2004, the percent of 15-year-olds who had consumed alcohol in the previous week had increased from 30% to 40% for boys and from 25% to 46% for girls. However, whereas there had been a slight decrease in the number of 15 year olds boys reporting drinking in the last week since 2002 (from 47% in 2002 to 40% in 2004), there was no change in prevalence for 15-year-old girls. More importantly, for first time prevalence of drinking in 15-year-old girls was higher than among boys of the same age. Similarly, comparisons internationally have found that boys of all ages tended to drink more regularly across the majority of countries and regions, but that countries differ in the magnitude of this difference (Currie et al., 2004). For example, in Italy, Greece and Poland differences between boys and girls are more marked; in Scotland, Wales, Austria and Finland differences are minor. It appears that girls' drinking habits are catching up to their male peers (Wright, 1999). Another important finding was that difference in prevalence of drinking between different age groups (i.e. 13 and 15 year olds) is becoming less; in 1990 three times as many 15 year olds than 13 year olds reported drinking in the last week, this being reduced to twice as many in 2004.

There is also evidence that the amount of alcohol, as well as the frequency of drinking is increasing. The SHS reported that between 1998 and 2003, mean consumption at age 15 had risen from 1.3 units per week to 2.6 for boys, and 1.3 units to 3 units for girls. This was greater when considering individuals who had drunk in the last week; mean consumption was 10.4 units for boys and 12.2 units for girls (the SALSUS survey reported that 15 year old boys consumed 13 units per week and girls 11 units). Again, young people in England consumed more alcohol than their counterparts in Scotland (Bromley et al., 2005).

Therefore, young people's experiences with alcohol vary sharply with age. The pattern has changed in recent times, with young people drinking larger quantities of alcohol on a more regular basis. However, perhaps the most important change is the increase in young people's reported experience of being intoxicated or 'binge drinking'. Thirty-one percent of 13 year olds and 56% of 15 year olds in the SALSUS survey reported having consumed five or more drinks on the same occasion ('binge drinking') at least once in the previous 30 days. This was higher for 15-year-old females than males (60% versus 52%). Most individuals who reported

having consumed alcohol in the previous week stated that they had been drinking at the weekend, for example 60% and 71% of 15 year olds reported drinking on a Friday and Saturday, respectively (SALUS, 2005). With regard to international comparisons, the reported first experience of drunkenness is younger for individuals living in the USA and Austria, followed by Scotland and England.

1.3.2.2 Alcohol and People with Intellectual and Physical Disabilities

Adults with Intellectual and Physical Disabilities

Despite the recognition of the poorer health experienced by people with intellectual disabilities, research examining the prevalence of alcohol use among young people with intellectual disabilities is scarce. There has, however, been greater attention on alcohol use among adults with intellectual disabilities. Overall these studies have tended to show that, despite a high variation in prevalence rates across studies, adults with ID (intellectual disabilities) consume lower rates of alcohol than their non-disabled peers (Beange et al., 1995; Lawrenson et al., 1995; McGillicuddy and Blane, 1999; McGuire, Daly and Smyth 2007; Pack et al., 1998; Rimmer et al., 1995; Robertson et al., 2000; Wells et al., 1997). Even the highest reported rates of alcohol use amongst people with intellectual disabilities are still well below that of the general population (Lawrenson et al., 1995). The nature of living arrangements appears to be one factor associated with alcohol use, with individuals residing in less restrictive residential settings drinking more (Rimmer et al., 1995; Robertson et al., 2000). In addition to the lower levels of supervision and monitoring of health behaviours seen in these settings, individuals living in the community may work or have more disposable income of their own to buy alcohol (Rimmer et al., 1995). Other factors associated with increased alcohol use and misuse include having a milder level of disability (Robertson et al., 2000; McGillicuddy and Blane, 1999), poorer alcohol refusal skills and being male (McGillicuddy and Blane, 1999). Levels of heavy drinking and alcohol-related problems also appear to be lower, although there is evidence that the proportion of people misusing alcohol is higher among adults with intellectual disabilities than in the general population (McGillicuddy et al., 1999).

Many individuals with intellectual disabilities who misuse alcohol also report experiencing negative consequences, such as physical and verbal aggression, changes in mood, exploitation by others, occupational difficulties, (i.e. being late for work, being fired, decreased work productivity or school grades), interpersonal difficulties with friends and family, sexual promiscuity, higher rates of rape, assault, physical and sexual abuse, and offending behaviour (Taggart, McLaughlin et al., 2006; Westermeyer, Phaobtong and Neider, 1988). Therefore, despite people with intellectual disabilities consuming less alcohol than the general population, drinking to excess has a similarly negative impact.

People with physical disabilities have been excluded from most large-scale surveys exploring health promoting and risk taking behaviours. The limited survey data in this area suggests there are no differences in reported lifetime prevalence of alcohol or substance abuse among people with and without disabilities, and in fact some studies have reported that alcohol and drug use to be proportionately higher in people with physical disabilities (Gilson et al., 1996; Moore and Li, 1998). For example, Turner, Lloyd and Taylor (2006) reported that the lifetime prevalence of alcohol dependence in individuals with a chronic condition or a physical impairment was 7.9% for males with a disability and 1.9% for females with a disability. This was higher (only statistically significant for males) than for the non-disabled control group (0.84% for males and 0.64% for females). It is frequently assumed that the cause of substance disorders in people with physical disabilities is the disability itself. However, Turner et al. (2006) noted that disability preceded the onset of any substance disorder in only 31% of the cases they examined.

Young People with Intellectual and Physical Disabilities

In an early epidemiological investigation in the USA, Huang (1981) found that in comparison to their non-disabled peers, adolescents (13 to 18 year olds) with mild to moderate intellectual disabilities were less likely to have drunk alcohol on at least two occasions over the previous year (32% versus 59%). In addition, drinking began on average 1.5 years later in the ID group. However, no data was collected on the amount of alcohol consumed, and the two samples differed in terms of racial and economic factors. The authors suggested that these young people with disabilities might rely on alcohol to achieve peer acceptance. Whilst this

explanation might be intuitively appealing, few studies have investigated young people's motivations for drinking.

In the USA, Gress and Boss (1996) compared drug use among students who were 'developmentally handicapped' (providing a similar definition to the UK's definition of intellectual disability) with non-disabled students in the USA. With regards to alcohol use, amongst students in grades 4 to 6 (roughly aged 9 to 12 years of age), 26% of those without disabilities and 23% of those with disabilities reported using alcohol in the last year. For participants in grades 7 to 8 (12 to 14 years), this figure increased to 51% for the non-disabled group and 46% in the ID group in participants. For participants in grades 9 to 12 (14 to 18 years), the difference between the two groups widened, with 72% of the non-disabled group and 54% of the ID group having consumed alcohol in the last year. Similarly, when asked about drinking alcohol in the last 30 days, this figure was higher for the ND group at age 9 to 12 years (11% versus 9%), 12 to 14 years (29% versus 23%) and 14 to 18 years (46% versus 36%). These findings seem to correspond with the survey data reported in section 1.2.3 for young people in the UK. By the mid teenage years a substantial proportion of young people report having tried alcohol. This study would suggest that there is a similar pattern for young people with intellectual disabilities in the USA.

Emerson and Turnbull (2005) conducted structured face-to-face interviews with 95 young people with intellectual disabilities aged 11 to 15 years, and compared their findings with data from 4069 non-disabled adolescents. In the month prior to being interviewed, 12% of the ID group said they had drunk alcohol compared to 22% of the non-disabled group. However, when asked if they had ever drunk alcohol, there was a smaller difference between the two groups (41% of the ID group and 50% of the ND group). Drinking at least once a month was negatively associated with parents using punitive practices and greater parental psychological distress. The authors noted that the ID group contained more males and had higher rates of poverty than in the comparison group.

Similar findings have been reported for young people with moderate to severe physical disabilities in the Canadian version of the Health Behavior in School-Aged Children Survey (HBSC; Steele et al., 2004). Compared to their same age peers, adolescents with physical

disabilities were less likely to have ever tried alcohol, or to drink wine, beer or liquor on a daily, weekly or monthly basis and to have been intoxicated more than once (see table 1.2). In fact, the highest percentage of adolescents with PD who ever tried alcohol or were regular drinkers was equivalent to the percentage of the youngest age group in the non-disabled sample.

Table 1.2: Percentage of adolescents with and without physical disabilities engaging in alcohol related behaviours (Steele et al., 2004).

Alcohol related Behaviour	Age (years)		
	11 – 12	13 – 14	15- 16
Tasted alcohol (at least once)			
Physical Disability (n = 311)	46.4	62.5	69.1
National Sample (n = 6998)	71.7	85.7	94.3
Use wine, beer or liquor (daily, weekly or monthly)			
Physical Disability (n = 289)	0	9.8	5.5
National Sample (n = 6845)	10.5	23.3	45.5
Been Drunk (more than once)			
Physical Disability (n = 317)	0	1	5.6
National Sample (n = 7003)	2.9	14.4	39.1

Britto et al. (1998) explored health behaviours in 321 young people (aged 12 to 19 years) with cystic fibrosis (CF) or sickle cell disease (SCD), reporting that compared to their age, race and gender matched peers, young people with CF or SCD were less likely to report drinking alcohol. For example, fewer participants reported ever using alcohol (CF, 45% versus 63%; SCD, 37% versus 70%), and for individuals who had tried alcohol, this was less likely to have occurred before the age of 15 (CF, 30% versus 53%; SCD, 24% versus 44%). In addition, fewer individuals with a physical disability than their non-disabled peers reported having consumed alcohol in the last 30 days (CF, 36% versus 59%; SCD, 33% versus 57%) or to have engaged in binge drinking in the past 30 days (CF, 18% versus 35%; SCD, 3% versus 18%).

Hogan, McLellan and Bauman (2000), using the same questionnaire as in the HBSC study above (Steele et al., 2004), reported that 11 to 16 year olds who reported having a disability were *more* likely to smoke, drink alcohol and become drunk than their non-disabled peers. Similarly, Blum, Kelly and Ireland (2001) reported that adolescents with mobility impairments were more likely to drink alcohol once a month or more than their non-disabled peers (24% versus 61%). However, these contradictory findings may be explained by the different definition of physical disability used. Whereas in the study by Steele et al., (2004), participants had a physical disability that was severe to moderate in terms of needs for assistance in daily living, the participants in the studies by Hogan et al., (2000) and Blum et al. (2001) had a much broader range of disabilities with varying levels of severity. Young people with more severe disabilities are likely to have greater adult supervision and consequently fewer opportunities to engage in health risking behaviours.

From this limited number of studies it would appear that adolescents with intellectual or physical disabilities use alcohol less frequently than their non-disabled peers. However, it would also appear that the magnitude of this difference is less marked for adolescents than it is for adults.

As research is limited in this area, little information is available beyond whether or not people have drunk alcohol. There is a need to develop a more detailed profile of drinking patterns in this population (i.e. frequency, amounts, situations, motivations) and employ longitudinal studies which will provide us with information of when and why young people may choose to drink or not. Simpson (1998) discusses how many authors also fail to discuss their most significant finding; why are levels of abstinence so high in people with intellectual disabilities? Abstinence may not be an active choice, but is likely to reflect wider issues of control and regulation (i.e. families or carers stopping individuals drinking). In addition, the focus of research in this area has frequently been on preventing people with disabilities from drinking alcohol, rather than helping them to enjoy safe levels of alcohol, which can play an important part in social and cultural life. For example, the following views were expressed by researchers in the field:

“Therefore, maintaining the nonuser status for those who do not drink, as well as preventing the progression of users into misuse is important.”

(McGillicuddy and Blane, 1999. p. 873.)

And:

“Only very infrequently is the right to drink and partake in the cultural practices in which alcohol plays a significant part recognised.”

(Simpson, 1998. p. 548).

Research examining alcohol consumption in young people and adults with disabilities has numerous methodological problems (Simpson, 1998). These include very small and/or unrepresentative samples, lack of control groups, and inconsistent use of terms like “substance use”, “substance misuse”, “substance abuse” and “drinking problems”. Many of the methods used to examine alcohol consumption are not appropriate for people with intellectual disabilities. For example, a multitude of measures have been used across studies, usually without any indication of their validity for use with individuals who have intellectual disabilities. Severity of intellectual disability and nature of physical disability are also likely to be important factors influencing alcohol use, however these factors have not always been considered. Taggart et al., (2006) discuss how people with borderline/mild disabilities may be at greater risk for developing alcohol related problems than individuals with more severe disabilities, owing to their greater levels of independence.

Finally, Simpson (1998) points out that alcohol consumption varies across countries and regions, depending on many factors such as local licensing practices, class, ethnicity, religion, and demography. Many of the studies cited above were conducted in the USA (for example, Edgerton, 1986; McGillicuddy and Blane, 1999; Rimmer, Braddock and Marks, 1995; Westermeyer et al., 1988) and as such their generalisation to the UK is questionable (Simpson, 1998). As people with intellectual and physical disabilities are more likely to live in poverty, be socially isolated and unemployed, these factors also need to be considered, along with issues of ethnicity or religion.

1.3.3 Sexual Health

1.3.3.1 Teenage Conceptions - Adolescents without Disabilities

It is interesting to examine trends in teenage conception rates over time in order to gain an insight into factors that have influenced it. A recent article discusses trends in teenage conceptions over the last 25 years (Brook Advisory Clinic, 2007; figure 1.9).

Young people today are less likely to get pregnant as they were in the 1970s, with rates falling from 82.4 per 1, 000 females in 1970, compared to 60.3 in 2004. Perhaps the most marked decrease in conception rates was witnessed from the mid-1970s to the early 1980s and mirrors the introduction of free contraception by the NHS. This was followed by a large increase in conception rates in the 1980s, which Brook attributes to young people's uncertainty over the confidential nature of providing contraception to the under 16s. In addition, cuts to family planning clinics and young peoples' services contributed to this rise, and it was proposed that increased unemployment meant that young people were less likely to delay having a baby (Brook, 2007). As young people's services expanded in the 1990s this trend was reversed and conception rates once again declined. Despite a significant increase from 1995 to 1998, coinciding with fears of possible side effects of the contraceptive pill, conception rates appear to be steadily decreasing. This was attributed to the introduction of strategies across the UK to improve sexual health and reduce teenage pregnancies (Brook, 2007).

Conception rates also vary by geographic regions and are linked with other factors, for instance deprivation. Young women from higher areas of deprivation opt to carry through to birth rather than termination more frequently and women under the age of 20 are five times more likely to be teenage mothers if they live in deprived areas (McLeod, 2001). In addition, factors such as having a history of generational teenage pregnancy in the family, low education attainment, being in or leaving care, being homeless or abused have been linked to teenage pregnancy (Social Exclusion Unit, 1999; Swann et al., 2003).

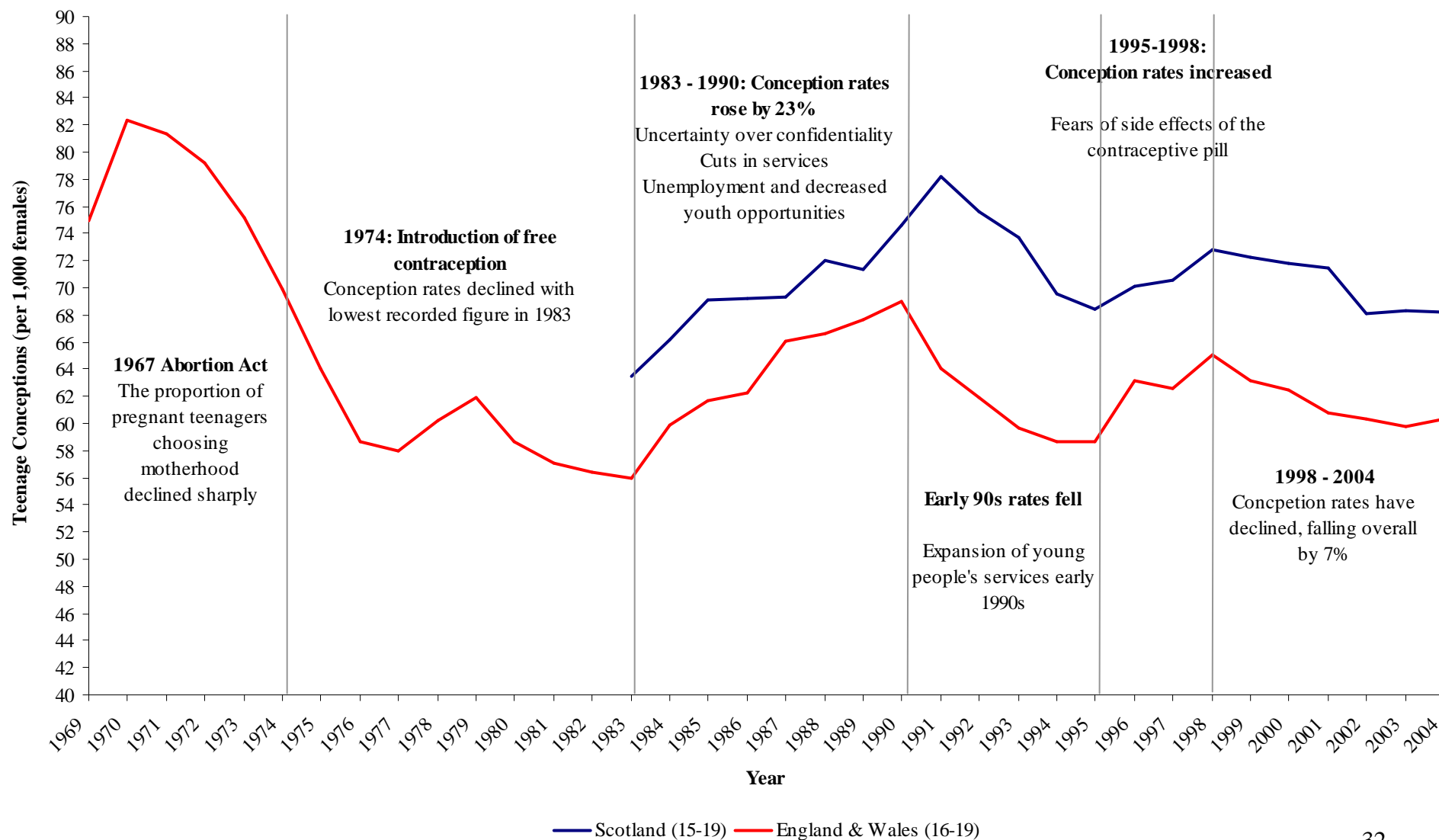
1.3.3.2 Sexually Transmitted Diseases - Adolescents without Disabilities

Sexually transmitted infections (STIs), including genital chlamydia, gonorrhoea, genital herpes genital warts, and HIV, are widespread and are continuing to rise (Macdowell et al., 2002). Although, the increasing numbers of STIs reported may in part be attributable to the success of efforts to encourage wider uptake of testing, this is unlikely to account for the observed rates (ISD Scotland, 2006).

In the second National Survey of Sexual Attitudes and Lifestyles (NATSAL, 2000), 11,161 men and women aged 16–44 years living in Great Britain were interviewed about their sexual lifestyles and attitudes. This survey found that amongst males who had ever had sexual intercourse (vaginal, oral, or anal), 10.8% reported ever having been diagnosed with at least one major STI, as did 12.6% of women. The most common were genital warts, genital Chlamydia, and there was substantial regional variation in the distribution of reported STIs.

Findings from the Scottish sample of the 1999/2000 NATSAL survey (Macdowell et al., 2002) reported that 9% of Scottish men and 13% of Scottish women reported having had an STI. In addition, individuals most at risk are young people, particularly females, gay and bisexual men, and some minority ethnic populations (e.g. Black Caribbean population). For example, more than 52% of chlamydia cases diagnosed in 2002 were among young people aged under 25 years of age, this rising to 65% among women aged under 30 years. There was also an increase of 66% in chlamydia cases diagnosed in women aged under 16 years of age between 2001 and 2002. Sexually transmitted infections are an increasing cause of morbidity amongst young people, in part a consequence of increased sexual activity (i.e. having a higher number of sexual partners; Johnson et al., 2001). HIV diagnoses are also continuing to rise, and whereas HIV transmission used to be predominately through sex between men, the main transmission route is now through heterosexual contact (Burtney et al., 2004). Sexually transmitted infections have a significant impact on the short-term and long-term health of both men and women, for example they may compromise the ability to bear children, or lead to pelvic inflammatory disease, ectopic pregnancy, cervical cancer and even death.

Figure 1.9: Rate of Teenage Conceptions in England and Wales from 1969–2004 for 15-19 year old females and in Scotland from 1983-2004 for 16-19 year old females (Brook, 2007).



1.3.3.3 Sexual Behaviour - Adolescents without Disabilities

Henderson et al. (2002) collected detailed data on the heterosexual sexual experiences of a large sample of 14-year-olds in Scotland. They reported at around the age of 13-14 many young people were engaging in sexual behaviours such as kissing using tongues. Seventeen percent of males and 13% of females in their sample had engaged in heavy petting (hand touching genitals/private parts) and 18% of males and 15% of females reported having had heterosexual intercourse. The authors reported that nearly all of the individuals, male and female, who reported having had sexual intercourse, also reported kissing with tongues (99%) and heavy petting (93%), suggesting a progression of sexual activities toward sexual intercourse. Oral sex did not appear part of this progression.

Findings from the Scottish sample of the 1999/2000 NATSAL survey (Macdowell et al., 2002) reported the median age for first intercourse for males and females aged 16-19 in Scotland is 16. This was a decrease from the 1990/91 survey, which reported the median age for males to be 17 and females 18 years. However, Wight and Henderson (2004) emphasise that reducing such behaviour to one age can be misleading, as this fails to consider the heterogeneity of young people's experiences. The Health Behaviour of School-aged Children (HBSC) examined age of first intercourse in a sample of 15 year olds from 30 different countries and regions. On average 28% reported being sexually active at 15 years of age, although there was marked heterogeneity across countries. This ranged from 9% of girls and 21% of boys in Poland reporting they were sexually active at 15 years of age to 79% of girls and 71% of boys in Greenland. England, Wales and Scotland also ranked in the top five with approximately a third or more of 15 year olds having had sexual intercourse. For those that were sexually active, the mean age of first intercourse was 14 years in England and Scotland and in Wales 14.3 years. It appears that sexual intercourse is not always planned amongst adolescents, for example Henderson et al. (2002) reported that 32% of 14 year olds who stated they had experienced sexual intercourse reported 'it just happened on the spur of the moment' and 20% stated that it was completely unexpected. A number of individuals also regretted intercourse, for example, with 32% of girls and 27% of boys reporting it had happened too early, and 13% of girls and 5% of boys felt it should not have happened at all. This coincides

with the finding from the NATSAL survey that women were more likely to experience regret after their first sexual intercourse (Macdowell et al., 2002).

Men in NATSAL survey were more likely to report having a higher number of sexual partners and having more than one partner at a given time (Macdowell et al., 2002). Other surveys have reported that young people have few sexual partners, for example with over half of 18 year olds having had one or two sexual partners (Johnson et al., 1994). The frequency of sexual activity also appears to be low; Henderson et al. (2002) reported that one-third of the sexually active participants had only had sex once. The NATSAL study reported that young people were more tolerant of one-night stands than those aged over 25 years, this being especially true for males (MacDowell et al., 2002).

With regard to contraception, the most common form of contraception used by young people appears to be the condom (Wight and Henderson, 2004). MacDowall et al. (2002) reported that younger respondents were twice as likely to use condoms the first time they had sexual intercourse than those aged 30 years or over. In addition, less than 10% of young people aged 16-19 interviewed used no form of contraception the first time they had sex (MacDowall et al., 2002). Henderson et al. (2002) reported in their sample of 14 year olds, less than 20% reported using no form of contraception. However, MacDowell et al., (2002) reported the main reason for contraception use appears to be to prevent pregnancy, with only a small number reporting they used condoms to prevent infections. The cross-national study of adolescent sexual behaviour in 15 year olds (HBSC, 2004) found that an average of 86% of boys and 85% of girls reported using any form of contraception at last intercourse; in Scotland this was 77.5% and in England and Wales, 84%.

1.3.3.4 Sexual Health: Adults and Adolescents with Intellectual Disabilities

“Considering the numerous and contentious discussions regarding the sexual rights of people with ID, there is surprisingly little information on the frequency and nature of sexual experiences in this group, and available findings vary greatly according to level of severity, living arrangement and information source”

(Servais, 2006. p. 49)

Relatively little research has been conducted about people who have intellectual disabilities in relation to sexuality. In addition, most research in this area has focused on sexual intercourse, as well as tending to emphasise the negative and problematic side of sexuality, for instance sexual abuse and inappropriate behaviour (Siebelink, de Jong et al., 2006).

An early study in the US by Timmers, DuCharme and Jacob (1981) reported that in a small sample of men and women ($n = 25$) with intellectual disabilities living in the community, 65% of men and 82% of women had engaged in sexual intercourse, although only 38% of men and 42% of women had sexual intercourse more than once a month. More recently, Szollas and McCabe (1995) interviewed 25 individuals aged between 16 to 45 years with mild intellectual disabilities about their sexual experiences. Compared to students without disabilities of a similar age ($n = 39$), individuals with ID were less experienced across a range of sexual matters, including sexual intercourse, contraceptive use, sexual interaction (i.e. breast petting, oral/genital contact), and dating and intimacy. With regard to current relationships, masturbation and homosexuality there were no group differences. The only area that individuals with ID had greater experience in was sexual abuse. McCabe (1999) reported that in a sample of 60 individuals with mild ID living in the community, 58% had experienced sexual intercourse and 31% were currently sexually active. This was significantly less than their peers with either physical disabilities or no disabilities.

McGillivray (1999) explored the sexual experiences of 60 Australian adults (aged 18 to 31 years) with a mild to moderate intellectual disability living in the community. When compared to undergraduate students without disabilities, fewer of the ID group were currently sexually active (18% versus 57%). However, in total 60% of the ID group were sexually experienced, as were 77% control group. Servais et al. (2002) examined contraception use in 397 women with intellectual disabilities aged between 18 and 46 living in Belgium. The majority of women had a moderate ID, but also included were women with a mild, severe or profound level of disability. Just over 7% ($n = 28$) were having or had previously had consenting sexual intercourse, 51% ($n = 204$) had not. For 41% of the sample ($n = 165$) it was not known. A further 60% of the women had never had a boyfriend. With regards to level of disability, 35% of individuals with a mild ID, 5% with a moderate disability and 0% with a severe disability were reported to have had or having sexual intercourse.

With regard to sexual behaviours of young people with intellectual disabilities, data is again sparse. An early study in the US by Chamberlain et al., (1984) explored sexual activity in 87 females aged 11 to 23 years with a mild intellectual disability. From interviews with parents and caregivers it was reported that one-half of the females had engaged in consensual sexual intercourse, which was similar to the rate in the general population. For females with a moderate or severe level of intellectual disability sexual intercourse was less frequent (32% and 9% respectively). Rurangirwa et al. (2006) reported that young adults with a history of developmental disabilities (including physical disabilities) were less likely to be sexually active in the last 6 months than their non-disabled peers. Specifically with regards to young people with intellectual disabilities, 58% had had one or more sexual partners in the last 6 months, compared to 79% of young people without disabilities. Using data from a longitudinal study of adolescent health (1994-1995), Cheng and Udry (2003) reported that at the age of 16, a lower proportion of adolescents with intellectual disabilities had experienced sexual intercourse than their non-disabled peers (24% versus 37% of boys and 8% versus 38% of girls).

Research exploring birth control practices and prevalence of STIs for adults and young people with intellectual disabilities is even more limited. Chamberlain et al., (1984) reported 48% of adolescent females had used contraception at some time in the past, with intrauterine devices and the contraception injection being preferred over oral contraceptives. Of 14 individuals interviewed who continued to be sexually active, 6 (43%) became pregnant. McCabe and Cummins (1996) found a much higher rate of pregnancy (61%) in a small sample of Australian women with ID living in the community.

More recently, Servais et al. (2002) explored contraception use in 397 women with intellectual disabilities aged between 18 and 46 living in institutions in Belgium. Compared with the general Belgium population, patterns of contraception use were different for women with ID. Fewer women with ID used contraception (60% versus 68%) and in particular, the oral contraceptive pill was used much less frequently (18.4% versus 46% in women with and without ID, respectively). Sterilisation was also more frequent in women with disabilities (22.2% versus 7%), as was the injectable contraceptive, depot-medroxyprogesterone acetate (DMPA; 17.6% versus <2%), both of which are methods used in populations who are poorly

compliant (Servais et al., 2002). Institutional factors played an important role in contraceptive use and choice (e.g. institutional policy concerning contraception and sexual relationships). The authors concluded that institutional policies played a more significant role in determining whether contraception is used and which type, than personal choice or medical reasons.

With regards to young people, Cheng and Udry (2003) explored contraceptive use and history of STIs or pregnancy in adolescents with low cognitive abilities and those with average cognitive abilities aged between 12 and 18 years. Amongst those who were sexually experienced, people with lower cognitive ability were less likely to report practicing birth control at first sexual intercourse than those with average cognitive ability (58% versus 65% in boys and 38% versus 63% in girls) or at most recent intercourse (60% versus 70% in boys and 39% versus 65% in girls). With regards to STIs, both boys and girls with a low cognitive ability were more likely to report having had an STI than their peers of average ability (8% versus 3% of boys, 26% versus 10% of girls). Similarly, girls of low cognitive ability were also more likely to have been pregnant (40% versus 18%) although this decreased when socio-demographic differences (i.e. race/ethnicity, family structure and parent education) were controlled for. Consistent with these findings, Rurangirwa et al. (2006), found fewer young people with disabilities than their non-disabled peers, who reported having had a sexual partner in the last 6 months, used protection against disease or pregnancy (27% versus 35%).

It has invariably been reported that people with intellectual disabilities hold more conservative or negative attitudes toward sexual activity (Szollas and McCabe, 1995; Lunskey and Konstantareas, 1998; Owen et al., 2000; Brantlinger, 1985), including sexual relationships (Owen et al., 2000), dating, condoms, homosexuality, oral sex, sexual intercourse, (Aunos and Feldman, 2002; Lunskey and Konstantareas, 1998) masturbation (Aunos and Feldman, 2002) and pornography (Lunskey and Konstantareas, 1998). Siebelink et al. (2006), however, discuss how these reported negative attitudes might be caused by caregivers concerns over sexual activity or by research bias. In Belgium, Lesseliers (1999) interviewed forty-six people with intellectual disabilities about sexuality and reported that attitudes towards sexuality tended to be negative. Whereas the participants did talk about intimate activity (e.g. caressing, kissing, cuddling, hugging), when asked if they would go further many answered “we don’t do that sort of thing” and others described sex as ‘dirty’ and ‘disgusting’.

Despite these reports of people holding negative outlooks towards their sexuality, and that people with intellectual disabilities seem to be less sexually active than their non-disabled peers, the picture is not as clear as it might appear. This is because it is also apparent that many adults and young people with intellectual disabilities are sexually active. There are a number of criticisms which limits the conclusions that can be drawn from the studies investigating the sexual attitudes and experiences of young people with intellectual disabilities, including small and non-representative samples, use of different research methodologies, and the inclusion of individuals with varying levels of disability and from different living arrangements (Servais. 2006). In addition, studies have tended to be very narrow in the type of sexual activity explored (i.e. sexual intercourse) and have relied on data given by parents or caregivers, as opposed to accessing information directly from the individuals themselves (Servais. 2006).

It is interesting that research information regarding sexuality is usually obtained from carers or those in positions of authority over the individuals with intellectual disabilities, as this reflects the limited control they have over decisions concerning their sexual needs. For example, there are issues of choice and control over contraception use. Although the pill has frequently been used by females with intellectual disabilities to manage menstrual problems, often women who are neither sexually active nor experiencing menstrual problems are given it (McCarthy, 1999). McCarthy's in-depth work on women with intellectual disabilities in the UK (McCarthy, 2009a, 2009b) has found that women feel that they have little choice and control about starting or stopping contraception use. Women did not always connect their contraceptive use with their heterosexual activity, suggesting that a 'just in case' approach was in operation (McCarthy, 2009a, 2009b). Oral contraceptives and barrier methods rely on user compliance, whereas injections and implants do not. Hence, Depo-Provera injections are commonly used for women with intellectual disabilities. Not only does this suggest that women have not been made aware of the possible side effects, such as long term health and fertility, but also that there are limited attempts to engage with their sexual health needs in an open and honest fashion.

1.3.3.5 Sexual Health: Adolescents with Physical Disabilities

With regards to young people with intellectual disabilities, there has been limited research on the sexual behaviours of young people with physical disabilities, and again research tends to focus on issues of abuse and exploitation (Cheng and Urdy, 2002).

Stevens (1996) reported that 29% adolescents aged 13-16 years of age with physical disabilities had experience dating, although 21% stated that by the age of 25 they would be married and 12% stated that they would have children. Similarly, Blum et al. (1991) reported that only 28% of young people aged 12 to 22 years with cerebral palsy and 15% with spina bifida reported having ever been on a date, compared to 54% and 44% of their friends, respectively. In addition, of those who had dated, this was infrequent (i.e. once a month or less). Only 7% of participants reported having a steady boyfriend or girlfriend. There is also evidence that dating starts later in young people with physical disabilities than their non-disabled peers (Kokkonen et al., 1991; Rintala et al., 1997)

With regard to developing more intimate relationships, Berman et al. (1999) reported that amongst Canadian adolescents (aged 16 – 18 years) with congenital physical disabilities, none had ever had a sexual relationship. Rurangirwa et al. (2006) reported that young adults with physical disabilities residing in the US were less likely to be sexually active in the six months prior to being interviewed than their non-disabled peers; 28% of young people with cerebral palsy, 49% with hearing loss and 50% visual loss reporting having one or more sexual partners in the last six months compared to 79% of young people without disabilities (and 58% of young people with intellectual disabilities). Cromer et al. (1990) explored the level of knowledge, attitude and activity related to sexuality in a group of adolescents and young adults (aged 13 to 21) with myelomeningocele (MMC), cystic fibrosis and without a disability. In participants with MMC, 28% reported previous sexual activity, as did 43% of participants with cystic fibrosis, compared to 60% of the control group. Thus, it would appear that young people with physical disabilities enjoy fewer opportunities to engage in sexual activity.

However, for young people with less severe physical disabilities, there is evidence to suggest that many are at least as sexually active as their non-disabled peers. In the US, Cheng and Udry (2005) used data from the National Longitudinal Study of Adolescent Health, to explore

sexual behaviour in adolescents aged 12 to 17 with and without disabilities. Of the 17,695 adolescents interviewed, 1153 adolescents were identified as physically disabled (687 were minimally disabled, 246 mildly and 220 severely). By the age of 16, 48% of boys with minimal disabilities, 44% of boys with mild disabilities, and 39% of boys with more severe disabilities said they had had sex compared to 37% of boys without disabilities. For girls, by the age of sixteen, 52% of participants with minimal disabilities, 36% with mild and 42% more severe disabilities had had sex, compared to 34% of girls without disabilities. It is also worth noting that girls with minimal or mild physical disabilities were more likely to have reported ever having been forced to have sex than their non-disabled peers. Thus, from this evidence the nature of people's impairments seems to make a considerable difference to their opportunities to engage in sexual activity.

Intuitively, level of disability may be considered an important factor in affecting sexual activity in people with disabilities. However, Surís et al. (1996) reported that visibility of the condition (i.e. cerebral palsy, muscular dystrophy, arthritis versus diabetes, asthma, seizure disorders) was not related to sexual activity (ever had sex or mean age at first intercourse). Similarly, Cromer et al. (1990) did not find a significant relation between the scores for severity of disability among individuals with spina bifida and their sexual experience. Nevertheless, young people with physical disabilities may face considerable obstacles to developing more intimate relationships, for example lacking self confidence, issues with incontinence, wheelchair use, functional limitations and communication difficulties (Verhoef, Barf et al., 2005; Wiegerink, Roebroek, Donkervoort et al., 2006). Even if these difficulties are unrelated to sexual activity per se, people need to have the opportunity to act autonomously and obtain privacy if they are to have an opportunity to develop more intimate relationships.

Sawyer and Roberts (1999) reported in a sample of 51 adolescents (aged 14 to 23 years) with spina bifida, 13 participants were sexually active. Of these, 11 used contraception and eight used contraception at each intercourse. A further three participants had been pregnant. Choquet, Du Pasquier and Manfredi (1997) found that girls with physical disabilities reporting at least one episode of sexual intercourse were more likely to be on the pill than their non-

disabled peers (58.7% versus 47.8%) and report more frequent histories of pregnancies (1.4% versus 2.9%). Condom use was similar across groups.

Data on the prevalence of HIV amongst people with intellectual or physical disabilities is limited, probably stemming from the assumption that these individuals are not at risk, despite the fact that some individuals are engaging in behaviours that may put them at risk of contracting HIV (Hatton, 2008). As highlighted in the previous section, although people with disabilities may be engaging in sexual activity at a lower frequency than their peers from the general population, many are indeed sexually active. In addition, some populations may be at greater risk of contracting STIs (Servais, 2006). Cambridge has pointed to a number of risk factors for people with disabilities catching STIs. These include risk of abuse, lack of knowledge, and homosexuality is rarely discussed or reported within this population (Cambridge, 1996). In addition to general sex education, young people with disabilities may also need to know about the effects of their own disability on their sexuality and reproductive function (Berman et al., 1999).

1.4 Conclusion

Reviewing the health behaviours of people with and without disabilities provides a complex and rather confusing picture. Firstly, with regard to eating and the other health behaviours, people's actions need to be understood within the broader social context, and factors such as social class and ethnicity need to be taken into account. Nevertheless, there would appear to be lower rates of alcohol consumption and sexual activity amongst the disabled groups. However, this was linked in part to the opportunities they had to exercise control over their lives. Indeed a number of decisions, such as regarding contraception, were often made by others with the goal of providing protection or reducing risk. At the same time, there were many people who did drink alcohol and had active sex lives. The unintended consequences of others trying to protect young people with disabilities from the possible consequences of their actions, was that they were perhaps less prepared than their non-disabled peers. Consequently, a key issue in this regard, is young people's knowledge of health related issues, and it is this topic that the next chapter will address.

Chapter 2: Health Knowledge

2.1 Introduction

Chapter 1 highlighted that many young people are engaging in behaviours that are putting their health at considerable risk, both presently and in the future. Poor eating habits, obesity, binge drinking, and unsafe sex practices not only adversely impact upon young people's physical and mental health but also have negative consequences for society as a whole. It is also apparent that these health-risking behaviours and their associated consequences are occurring at increasingly younger ages. Although young people with intellectual and physical disabilities appear to be engaging in some health-related behaviours at a lower rate than their non-disabled peers (i.e. alcohol use, sexual activity), it is apparent that many are engaging in behaviours placing their health at risk.

It is important to acknowledge that young people with disabilities share the same health needs and aspirations as their non-disabled peers, and the content of health education should therefore cover the same issues. However, the health information may require to be delivered in a different way, and the particular social circumstances of individuals with disabilities and their support needs also need to be recognised. Young people with disabilities may face many attitudinal and structural barriers to learning about health, have a greater dependence on parents and carers, be more isolated from peers and have fewer opportunities to engage in social activities or experiment with behaviour. Together, these factors may limit access to formal and informal sources of health advice and information, which in turn can impact upon health knowledge and understanding (Fraser and Sim, 2007) and this is discussed further in chapter 3.

This chapter provides an overview of the research examining the health knowledge of children and young people with and without disabilities in relation to healthy eating, alcohol, and sexual health. It is important that educational programs adopt a holistic approach, addressing not only knowledge, but also attitudes and experiences. However, empowering adolescents to make sensible and informed decisions about their health requires them to have some knowledge of the consequences associated with different behaviour. Therefore, this chapter

will review the research findings covering the health knowledge of young people with and without disabilities. However, it should be noted at the outset that there has been a paucity of research concerning those with disabilities.

2.2 Research Methods Used in Health-Related Research

Various interview formats have been employed to elicit children and young people's health related knowledge. These formats have ranged from multiple-choice, self-administered questionnaires to semi-structured interviews and focus groups, each with unique advantages and drawbacks. Closed-ended questions have been commonly employed in health-related surveys and studies. These are advantageous in that they allow data to be collected with ease and can provide standardised information. They also make it easier for children respond to questions of either a difficult or sensitive nature, for example in studies relating to sexual health or AIDS. However, exploring health concepts and facts in isolation through structured questionnaires tells us little about the complex nature of children's thinking in relation to health, or how their understanding develops. For example, in the area of healthy eating, several studies have explored children and young people's knowledge of specific nutrients and healthy eating guidelines. However, evidence presented later in this chapter would suggest that children do not spontaneously group foods together according to the same classification systems used by experts (i.e. into sugars, fats, proteins). The face validity of questionnaires based around these expert concepts is therefore brought into question.

Using structured questionnaires can also lead to an overestimation of an individual's level of understanding and fail to identify misconceptions (Schonfeld et al., 1993). For example, Lieberman et al. (1992) found that children in their study had a clear notion that smoking can cause cancer and that you can die from cancer. However, more complex and abstract ideas like damage to the body beginning as soon as one starts to smoke, that damage accumulates over time and that other factors can play a role in increasing or reducing the risk of disease were not necessarily understood. Without this understanding young people may lack convincing arguments as to why smoking or other health-risking behaviours should be avoided (Lieberman et al., 1992).

To overcome some of the difficulties with more structured approaches, researchers have turned to qualitative techniques to tap into children and young people's own understandings of health. However, an important drawback of using qualitative methods is that just because something goes unsaid does not necessarily mean that the individual does not have that knowledge. This is frequently the case with younger or less verbal individuals where there is the danger of underestimating their abilities. The difficulty therefore lies in developing methods that will ensure that we are adequately accessing what respondents do and do not know. In two studies exploring children and young people's perceptions of healthy eating, Noble et al. (2003) got participants to create a healthy meal from a selection of photographs of foods, and asked them to provide an explanation for their choices. The authors used foods that were familiar to the children (foods typically served in their school cafeteria), thereby making the task relevant and authentic to children's experiences. Thus, innovative methods can help to obtain the views and knowledge of young people.

Another criticism of many of the studies in the area of health is that they are not adequately informed by theory. This has implications for health education interventions. For instance, in relation to sexual health, Fisher and Fisher (1992) concluded that the ineffectiveness of many interventions was due to the atheoretical nature of the materials used. Similarly, there is evidence that sex and relationships education is more effective in changing attitudes and behaviour when theory-based (Health Scotland, 2008). One perspective that has been applied children's understanding of health is the intuitive theories perspective (Wellman and Gelman, 1992). This approach is briefly considered here.

The Intuitive Theories Perspective

As discussed above, studies have tended to assess children and young people's health awareness by assessing their knowledge of isolated concepts and facts, which tells us little about how knowledge is organised. The intuitive theories perspective argues that young children spontaneously and actively build intuitive theories about their world, for example in the domains of physics, psychology and biology (Au, Romo and DeWitt, 1999; Carey, 1985, Wellman and Gelman, 1992). These theories outline the kinds of entities to be found in each domain and the central causal mechanisms or processes involving these entities, which allow

individuals to reason about relevant phenomena. These theories begin to develop early in childhood and are frequently based on observable events (Carey, 1985). With the acquisition and organisation of knowledge in a domain, theories might become more specific and differentiated, or become fundamentally different theories altogether (Sigelman et al., 1996). An illustration might be children's concepts of body functioning. Carey (1985) argues that before the age of 9 or 10 years a child's explanations of biological phenomena are based on a psychological theory of biology, and that young children remain largely ignorant of the physiological mechanisms involved. Hence children view bodily processes in terms of the body's needs and desires, and tend to perceive bodily processes to be under intentional control. They later develop an 'intuitive' biological theory focusing on the importance of body functioning for the maintenance of life (Au et al., 1999; Carey, 1985). It is important to note, however, that there is a disagreement between researchers as to whether children do indeed have a theory of biology. For example, some believe that theory of biology develops much earlier than Carey claimed and is independent from other domains (i.e. psychology) from the beginning (Keil, 1992, 1994). Keil also places greater emphasis on genetic or innate constraints on theory acquisition (i.e. constraining information children notice and use). More recently, Hatano and Inagaki (1997) argue that even pre-school children have an understanding of biology that is separate from their understanding of psychology, arguing that this knowledge develops from daily experience and is influenced by religious and cultural beliefs. These different views have implications for the teaching of biology and its related health topics, for instance how and when biology should be taught (Teixeira, 2000).

It has been argued that health education often involves presenting children and young people with discrete facts about health. Information might be taught about the nutrients present in foods, the physical properties of alcohol, and risk and non-risk behaviours for HIV. Yet such educational approaches provide little in-depth information about the relationship between these health behaviours and their impact upon the body (Au et al., 1999; Sigelman et al., 2004). For example, children may know many facts about the effects of alcohol (it makes you sick, stagger, etc.), yet still be unable to explain how alcohol causes these effects. These facts are understood only in terms of input-output relationships, but the children lack an understanding of the casual mechanisms involved. Au and colleagues (1996, 1999), in exploring children's (aged 5 to 14 years) folkbiology, or intuitive theories about living things,

reported that when explaining biological events few children referred to biological causal mechanisms. Instead, children tended to favour mechanical causality in their explanations. For example in explaining why an item of food left on a table overnight would have more germs on it, children focused on the movement of germs, such as they fell from the air into the food.

This begs the question why understanding causal biological mechanisms is so important? Au et al., (1999) argue that having a coherent basis to connect numerous facts about health and illness allows us to reason in novel situations, and therefore makes it more likely that such knowledge will influence actual behaviour. In addition, people are better at remembering conceptually coherent information than unconnected material, and such it can reduce the cognitive load of having to learn a list of seemingly disjointed facts (Zamora et al., 2006). There is evidence that even young children can be taught these biological causal mechanisms and this increases ability to reason in novel situations (Au and Romo's, 1996; Sigelman et al., 1996; Zamora et al., 2006).

2.3 Healthy Eating, Alcohol and Sexual Health Knowledge

2.3.1 Healthy Eating Knowledge

Before reviewing the studies in this area, is it important to acknowledge that although knowledge is a necessary, if not sufficient, condition for people to make positive changes to their diets, there are a multitude of factors operating against dietary change. For example one study reported that 60% of Scottish adults in their sample had no intention of changing their diets, simply because they did not want to (Anderson et al., 1994). Of the individuals who did want to change their diet, barriers to change included cost (23%), existing food preferences (13%), lack of willpower (6%), habit (4%), and family influences (4%). Societies have traditional eating patterns that have developed over many years, in part determined by the availability of foods locally, as well as by cultural and religious beliefs (Scottish Executive, 2003c). For instance, Anderson et al., (1994) argue that Scots living in urban areas have been disadvantaged with regard to access and availability of fruit and vegetables. They discuss the lack of open-air markets with local produce found in other countries and how many of the independent greengrocers stock only traditional fruits (such as apples, oranges, bananas, pears

and grapes) and ‘safe’ vegetables. Even though the availability of fresh produce has changed recently, with a greater variety of foods being sold, such habits are hard to change. Blanchette and Brug (2005) discuss how availability and accessibility of fruit and vegetables is associated with consumption in children. Clearly, the diet that children become used to at home will influence their experience of food and attitudes and beliefs about what they eat.

These factors may help to account for differences reported across various regions in the UK and abroad. As was illustrated in chapter 1, eating patterns, alcohol consumption, and conception and STI rates vary by country or region. For example, with regards to fruit and vegetable consumption across the UK, the Expenditure and Food Survey showed that people in Northern Ireland, Scotland, Wales and the North of England consumed less fruit and vegetables than those in the South East, South West, East or London (www.heartstats.org). Studies with adolescents have shown Scottish teenagers to have significantly lower intakes for certain micro- and macronutrients (i.e. fibre, magnesium, phosphorus, carotene, non-processed vegetables, non-fried potatoes, skimmed milks, fats high in polyunsaturated fats) than their counterparts in England and Wales (Crawley, 1997). As many of the studies cited in this chapter are drawn from different regions across the UK and abroad, it is important to bear these differences in mind when comparing across countries.

One factor that seems to heavily influence food choices is socio-economic status (SES). Section 1.3.1 showed that the Scottish dietary targets were the least likely to be achieved in areas of lower socio-economic status. Dobson, Beardsworth, Keil and Walker (1994) reported that individuals who were on a low income often tried to maintain conventional eating patterns or what they considered to be an ordinary diet. They believed that to rethink their diet would involve trial and error, something that they could not afford. In addition, this study reported that children of low-income backgrounds received more of their favorite foods, such as chips, burgers, and fish fingers, than their affluent friends. They were given the foods they liked so to avoid waste, as mothers felt they could not take the risk of buying more nutritious foods that their family might not eat. Parents also reported that they did not want their children to seem different from their peers and so gave them treats, such as chocolate and crisps. People of lower SES may also be more likely to buy foods that are value for money and energy dense (Stephoe et al., 2003). As discussed in chapter 1, parents of children with disabilities may have

greater financial restraints stemming from the health care needs of their child, meaning fewer resources can be spent on making healthy meals (Minihan et al., 2007).

For children with and without disabilities, food may also be used as a reinforcer of desired behaviours (Minihan et al., 2007), and Hart et al. (2002) reported a common occurrence of what they termed ‘food deals’, where a specific food was allowed only after the consumption of another, such as a pudding after a main meal. Hart et al. also found gender differences in relation to parental rules over food consumption, with girls reporting greater restriction from parents. Conversely, boys reported more rules relating to the obligation to finish *all* the food given. The authors argue that this reflects the belief that boys should be ‘nurtured with food’ and ‘fed up’, whilst girls receive more information and messages on dieting and food restraint.

People also have lay beliefs about foods which have been passed on through generations. In the study by Anderson et al., (1994) one participant was reported to say “*my granny had a boiled onion every night before she went to bed. It’s supposed to keep your blood from clotting and thickening and she did that till she was 97 or 98*”. Participants in this study also had beliefs about the acceptability of eating different foods, for example that salads were not to be eaten in the winter, but ‘heavier’ root vegetables should. McKie (1999) interviewed individuals’ aged 75 years and over in Scotland with regards to “Healthy eating”. To them healthy eating was thought of as eating ‘proper meals’ which were “*traditional in composition, comprising at least two courses, with one course including meat or fish, potatoes and a vegetable. The other course would either be soup or pudding or a piece of fruit*”. This belief had been instilled into them as children and was still of great importance in their dietary regime. Although these studies were with older populations, the importance and pervasiveness of lay beliefs in influencing dietary behaviours is illustrated. Peer beliefs are also important in influencing people’s food choices, as of course is personal preference (Blanchette and Brug, 2005).

Evidence suggests that people are aware of the need to change and improve their diets, yet remain confused how to actually carry this change through. Recent findings from a survey in America (IFIC Foundation Food and Health Survey, 2006) reported that 88% of adults were unsure of the number of calories required a day and were confused with regards to how

calories from different food groups (i.e. fat, carbohydrates) can contribute to weight gain. In England, the Health Education Monitoring Survey (HEMS) monitors the set of health promotion indicators for health-related knowledge, attitudes and behaviours set out in *The Health of the Nation* White Paper (Department of Health, 1992). The report from 1996, which asked about individual's perceptions of a healthy diet, found that only 16% of individuals mentioned three out of four core dietary recommendations; 67% stated more fruit and vegetables should be consumed, 45% mentioned less fat, 27% stated more fibre, and 20% said we should consume more carbohydrates (Hansbro et al., 1997). Women tended to have better knowledge than males, as did individuals of higher SES and education level.

To make healthy choices about food, consumers need to consider a wealth of information. This includes a need to understand the different components of food and their relative healthiness (for example fats, carbohydrates, sugars) and also to be able to incorporate these foods into healthy eating patterns (Paquette, 2005). Being able to reiterate the current guidelines for healthy eating, although important, will not suffice; consumers need to understand these principles and incorporate them into their everyday life.

2.3.1.1 Healthy Eating Knowledge in Children and Young People without Disabilities

In order to identify the current state of knowledge in relation to healthy eating in the general public an overview of people's understanding and perceptions of healthy eating is provided, closely mirroring key government guidelines set out in the SDAP and discussed in chapter 1. The aim is to provide an insight into where misconceptions exist and to highlight possible reasons why nutritional messages are not being translated into healthful behaviours.

In a review of the literature regarding people's perceptions of healthy eating, Paquette (2005) reported that fruit and vegetables were the most frequently cited element of a healthy diet or healthy eating. With regard to children, even those as young as 5 or 6 years more frequently cite fruits and vegetables as being better for you than other food groups (Paquette, 2005; Povey et al., 1998; Parmenter, Waller and Wardle, 2000; Murphy et al., 1995; Lytle, Eldridge et al., 1997; Seaman, Woods, Grosset, 1997; Edwards and Hartwell, 2002; Oakley, Bendelow et al., 1995). However, individuals tend to place more importance on the consumption of fruit

than they do vegetables, with children being better at recognising different fruits than they are vegetables (Oakley, Bendelow et al., 1995; Edwards and Hartwell, 2002). Although young children seem to be aware of the importance of including fruit and vegetables in the diet, they often lack coherent rationales as to why this is the case. For instance, a study in New Zealand found that teenagers knew that fruit and vegetables were good for them but fewer than half discussed vitamins and of those, very few knew what these did in the body (Hill and Casswell et al., 1998). Similarly, Michela and Contento (1984) asked 5 to 11 year olds about their knowledge of vitamins, and although a number of children knew they helped to keep the body healthy, they had little other knowledge. However, to understand how vitamins or other constituents of food influence health, children need some understanding of how food is processed and transformed by the human digestive system. Teixeira (2000) used an intuitive perspective to examine children's models of human digestion, or what their causal explanations were of what happens to food from ingestion to excretion. They reported that there is a gradual change from the years four and ten, in terms of increasingly describing the function of organs or a biological basis for digestion. At age four, children see the abdominal area as an empty space, where all food intake is contained. However as these children do not discuss different organs, no transformations to food occur and food stays as it is in the body. These children use their knowledge of everyday experiences to reason how matter will leave the stomach area, for example through gravitational movements where it can then accumulate in the legs or arms, stretching the body and causing growth. The oldest children understand part of the ingested food is absorbed by the body (elements that are good for the body), while another part is not. These children have some understanding that distinct organs or substances (e.g. acid) are involved that can transform the food into substances the body can use (i.e. blood or cells). However, the authors noted that most children did not understand that food is chemically transformed by substances in the body.

Paquette (2005), in her review, also reported that fat, sugar and salt were mentioned the most frequently by children, young people, and adults with regard to foods to be *avoided* in a healthy diet. Murphy et al., (1995) reported although many children aged 5 to 6 years were able to identify foods high or low in fat or sugar, many children gave inaccurate responses, stating that fruits and vegetables were high in fat. Moreover, they frequently confused foods that had high salt, sugar and fat content with one another. Again, this suggests that although

these young children were aware of what foods are ‘good’ and ‘bad’ for you, they had difficulty identifying foods that were high in a particular nutrient.

Lytle et al. (1997) asked children aged 5 to 12 years what foods they should consume if they wished to consume a diet low in fat. Younger children (ages 5-8 years) discussed avoiding high fat foods such as desserts, sweets, whole milk and chips, whereas older children (8-10 and 10-12 years of age), also mentioned healthy foods. Only a small number of the younger children considered using low fat alternatives, such as skimmed or semi-skimmed milk. This suggests that younger children may focus more on avoiding certain foods considered ‘bad’ or unhealthy, rather than including more healthful foods. However, it is also possible that young children are responding in a way they think the researcher wants them to as opposed to what they actually believe. The questions in the study were very structured, and therefore children may have been giving idealistic responses (i.e. “we should never eat sugar”). In the studies by Noble and her colleagues children had clear views on what foods are ‘healthy’ and ‘unhealthy’, perceiving healthy eating as the absence of fat and sugar or the presence of vitamins and nutrients. Few mentioned the idea of balance or moderation when asked to choose healthy meals. Instead, individuals tended to focus on the healthiness of individual items rather than balance within a meal. However, this leads to a tendency for children to view healthy eating as omitting certain ‘bad’ foods. Further evidence for this type of thinking comes from a study conducted by Rasnake, Laube et al., (2005). They interviewed 136 children aged 10-13 years old about their nutritional judgements in relation to healthy eating. They reported that 50% of the children used ‘dose insensitivity’ thinking, the belief that if something is harmful in large amounts it is also bad for you in small amounts. Without an adequate knowledge of how to compensate with other food groups, or how these less healthy foods can be included in a balanced diet, as they contain essential nutrients, this becomes unhealthy in itself. Therefore, the authors argue that we need to move away from concepts such as ‘good’ and ‘bad’ and individual foods toward concepts of balance and of whole meals and diets. Moreover, there is a need to be aware how people interpret health messages (Rasnake, Laube et al., 2005). These studies have begun to demonstrate *how* children think about food and *why* they frequently hold misconceptions.

As stated above, children and young people may think about and classify foods in ways that do not always correspond with the systems used by health experts (Michela and Contento, 1984), thereby making it difficult for dietary recommendations to be understood and executed. Michela and Contento (1984) suggest it is difficult for children to utilise such classification systems due to insufficient cognitive development. These authors draw on work by Inhelder and Piaget (1964), demonstrating that children at lower levels of cognitive development tend to rely on perceptual or sensory cues which are quite concrete. Only at later stages does this become more advanced, with children relying on abstract bases to classify objects and being able to categorise items into more than one class simultaneously (Michela and Contento, 1984). This would fit with the finding that younger children view food as either being 'good' or 'bad' and have difficulty with abstract concepts like nutrients, particularly if they are 'invisible'. In their study, Michela and Contento (1984) asked 115, 5-11 year olds to classify 71 foods into groups using any criteria they chose. They found that all children used the dimensions of sweet versus non-sweet foods (i.e. cakes and cookies versus other foods) and main meals versus drinks versus breakfast foods to classify foods. The authors interpreted this to show that the perceptual (i.e. sweet taste, liquid or solid) and functional (i.e. when it is eaten) properties of foods influenced children's food classifications, and this was regardless of their cognitive developmental level. Dimensions such degree of processing (i.e. fresh and less processed versus cooked and more processed foods) and animal versus plant origin (i.e. meats poultry and fish versus fruit and vegetables) influenced only the children of higher cognitive level. The bases for food classification not only became more abstract with increasing cognitive level, but they also became greater in number. Therefore, children's groupings did not match the systems used by health experts and the authors suggest that by using children's 'naturally occurring conceptualisations', we are better positioned to deliver effective education strategies. Unfortunately, to date, few studies have attempted to do this, although there are a growing number of qualitative studies that are moving towards this position.

Even young children demonstrate an awareness of the impact diet can have upon health. Murphy et al. (1995) reported that 5 to 6 year olds in their study knew that eating too much junk food, fat, snacks, and chocolate etc., could lead to someone becoming fat. In addition, they were aware that possible consequences of being overweight could be teasing, greater difficulty doing activities and a general impact upon one's health. Dixey et al. (2001) reported

that the main consequence of an unhealthy diet cited by 9 to 11 year olds in their sample was its effect upon the heart, specifically causing blocked arteries. In a series of focus groups with one hundred and fourteen, 7-11 year olds, Hart, Bishop and Truby (2002) found that the most common reason mentioned for classifying foods was their associations with health consequences, even though many of these associations were incorrect. This awareness of the relationship between diet and health, even if at a rudimentary level, has been found in a number of other studies with children and young people (Oakley et al., 1995; Noble et al., 2000; Noble et al., 2003).

Overall, it would appear that adults and young people seem to have a clear idea of the importance of including fruit and vegetables and avoiding fatty foods, foods high in sugar and salt in a healthy diet. In addition, children and young people seem to have a general sense of the impact that diet can have upon health, their knowledge of *how* food impacts health or *why* certain foods are important is more limited. However, to make healthy choices about food, consumers need to consider a wealth of information. This includes a need to understand the different components of food and their relative healthiness (for example fats, carbohydrates, sugars) and also to be able to incorporate these foods into healthy eating patterns (Paquette, 2005). Being able to reiterate the current guidelines for healthy eating, although important, will not suffice. Consumers need to understand these principles and incorporate them into their everyday life.

Gender is in fact an important factor that influences dietary behaviours, with females having greater knowledge of fruit and vegetables (Paquette, 2005), fat (Paquette, 2005), carbohydrates, fibre (Buttriss, 1997), as well as healthy eating in general (Parmenter et al., 2000; Frobisher, Jepson and Maxwell, 2002; Hansbro et al., 1997) and its impact upon health (Hart, Bishop and Truby, 2002). One potential reason for this greater knowledge is that women have been found to report more interest in cooking and health in general than men (Frobisher et al, 2002).

2.3.1.2 Healthy Eating Knowledge in Children and Young People with Intellectual and Physical Disabilities

Unfortunately, few studies have explored nutrition knowledge and understanding in people with disabilities. The few that have tend to rely on structured questionnaires and therefore fail to explore understanding in any depth. Golden and Hatcher (1997) interviewed 57 obese and non-obese adults with either mild or moderate intellectual disabilities. Participants lived in group homes, supervised apartments, or foster homes and were on average aged 39.9 years. Multiple-choice and yes/no questions (with visual stimuli) were used to ascertain participants' knowledge about nutrition, weight loss and exercise. Unsurprisingly, adults with a mild level of disability were more knowledgeable than those with a moderate level of disability. However, respondents who were classified as obese had *greater* knowledge than individuals who were not obese, emphasising the fact that factors other than knowledge influence the development and maintenance of obesity. Although the questionnaire demonstrated good reliability and internal consistency, it was fairly time-consuming and therefore may not have been optimal for people with intellectual disabilities.

Illingworth, Moore and McGillivray (2003) developed the Nutrition and Activity Knowledge Scale (NAKS), which assessed knowledge about: nutrients and food groups; fat, sugar and caloric content of foods; weight and weight loss; and the impact and benefits of activity and exercise on health. The questionnaire consisted of 35 multiple-choice items, which were accompanied by 'Clip Art' cartoon style pictures. An example question is "which food has the most fat (accompanied by pictures of popcorn, vegetable kebab, potato chips and orange)?" The questionnaire demonstrated a two-factor structure: weight/weight control and nutritional value of food. Seventy-three adults aged 18 to 63 years participated in the study, 11% of whom had a mild intellectual disability, 73% moderate and 16% severe. Knowledge of both the weight/weight control subscale and nutritional value of food subscale was reported to be low. Participants frequently knew which foods were 'good' and 'bad' for them, although they were unable to articulate why or reasoned that this was true because a carer had told them. Similarly, with regards to the questions on exercise, an activity was classed as either good or bad for reasons unrelated to the health benefits, for example 'watching TV is good as it keeps me out of trouble' or stating that exercise was bad because an existing medical

condition prevented them from engaging in it. The authors concluded that in exploring nutrition and exercise knowledge, it is important to consider the participants' possible interpretation of the questions, as well as taking account of their level of understanding.

Jobling and Cuskelly (2006) developed the Health Knowledge and Behaviour Interview (HKBI) to explore health knowledge and health behaviour in 17 girls and 21 boys with Down syndrome (aged 11 to 18 years) and their parents living in Australia. Most of the respondents indicated that they understood the association between eating and health, although only two of them could explain what this relationship might be. When respondents were asked to name a healthy food, almost half gave an appropriate response, however a third named foods that were high in fat (for example chips) and the rest could not provide a response. In a second part of the questionnaire, participants were asked to place 22 cards onto a healthy eating pyramid in one of three areas, "to be healthy eat a lot", "to be healthy eat sometimes", "to be healthy eat only a little". Almost half of the participants were able to place over half of the cards correctly. When asked to construct a healthy lunch using the cards, more than a third of the sample included coke, chips and sausage rolls, and almost half selected hamburgers. On the positive side a quarter of the sample also chose fruit, and after coke, water was the most frequently chosen drink. Although participants were not systematically asked about their choices of foods, the authors noted that many foods were chosen based upon the child's preferences. The authors suggested that the participants' poor knowledge and lack of understanding was likely to be related to their lack of involvement in choosing and preparing foods in their everyday lives. In addition, as noted earlier for people with physical disabilities, young people with intellectual disabilities may develop a different relationship with food compared to typically developing children. For instance, food may be more commonly used a reward for good behaviour, or to motivate the child (Jobling and Cuskelly, 2006; Minihan et al., 2007). This may lead to children viewing food in terms of rewards and punishment, but not so much in terms of health.

The 'Healthy Lives' study adopted a qualitative approach to examine different aspects of health in the lives of 30 adults (aged 19 to 79 years) with intellectual disabilities living in the community. As part of this study, Rodgers (1998) examined the role of food in these individuals' lives. With regards to knowledge of healthy eating, participants were asked if they

knew which foods were healthy and which were not. Only 7 out of the 30 adults interviewed had a reasonable idea of what constituted a healthy diet, and just over half were unsure where further information about healthy eating could be obtained. However, it was also reported that many of these individuals had little control over what they ate, with 22 of the 30 individuals having meals planned for them by staff or carers, and only four of them took part in food shopping. Another theme that came through was that when carers or staff did try to encourage healthy eating it was through controlling their food intake, rather than negotiating with the individual concerned. Consequently, learning about health eating is not merely an educational or intellectual endeavour, it is also a process of socialisation.

2.3.2 Alcohol Knowledge

2.3.2.1 Alcohol Knowledge in Children and Young People without Disabilities

In reviewing the literature on young people's alcohol knowledge, Wright (1999) noted that little attention has been given to this area, despite the abundance of reports and surveys exploring young people's drinking behaviours, attitudes, values, beliefs and expectancies. She noted that whilst reports and large-scale surveys on adolescent drinking have asked about knowledge, detailed findings are frequently not reported unless they relate to actual drinking patterns. Having a good knowledge base is imperative if young people are expected to make informed decisions about their alcohol intake. By exploring what young people know about alcohol, health education strategies can be rooted in their existing knowledge and understanding, addressing any gaps and misconceptions. In chapter 1, it became clear that it is important to deliver health education at a young age, not merely because young people are engaging in health risking behaviours and at an increasingly younger age, but because health education strategies are likely to be more effective in *preventing* the initiation of risky behaviours rather than altering existing ones (Brown, Reynolds and Brenman, 1994). Numerous studies have demonstrated that even very young children have some awareness and knowledge of alcohol prior to personal experience. For example, Noll and his colleagues, used various activities such as pictures, smelling games and object sorting tasks to show that young children can identify alcoholic beverages and know the norms and appropriate social contexts for their use (e.g. Noll, Zucker and Greenberg, 1990). Moreover by the time they are at

primary school, children can describe the symptoms of drunkenness (Casswell, Gilmore, Silva, and Brasch, 1988).

More recently there has been a greater focus on young people's awareness of sensible drinking messages, usually assessed in terms of knowledge of 'units' of alcohol and daily or weekly benchmarks for alcohol intake. Yet the power of sensible drinking messages is in their accessibility and relevance, so that the public can understand them and apply them to their own drinking. Consequently, it is important that the public knowledge and understanding of these messages is assessed. In 1995, the Department of Health (DoH) proposed a change in how intake is measured from weekly to daily benchmarks, the former it was argued masked episodes of heavy drinking. For example, young people frequently concentrate their drinking into a smaller number of sessions (i.e. weekends) rather than spreading their intake over the week (section 1.3.2.1). The current government advice for men is that consistently drinking four or more units a day is not recommended, as is more than three units a day for women (Department of Health, 1995 and Department of Health, 2004). It appears that a number of adults in the UK have a poor awareness of these benchmarks (Hansbro et al., 1997; Ladder and Goddard, 2006; Webster-Harrison, Barton et al., 2002). With regard to young people, the evidence is more limited. Plant et al. (1990) found in a sample of over 6,000 English teenagers (aged 14 to 16 years of age) 56% of males and 52 % of females believed that a single measure of whiskey was stronger than a pint beer. Twenty-six percent of males and 28% of females believed that all beers contained the same amount of alcohol, and the same number believed that a glass of wine has more alcohol than a pint of cider. Furthermore, the authors reported that over one third of males and one quarter of females thought it was safe to drive after consuming one or two drinks. Six percent also stated that drinking alcohol made you more alert.

Studies have shown that when people are asked to pour their own drinks they often pour more than standard volumes (Gill and Donaghy, 2004; Lemmens, 1994; Kaskutas and Graves, 2000; White et al., 2003). In Scotland individuals are as likely to buy alcohol from supermarkets as from licensed premises, the most frequently cited place to drink being the home (Lader and Meltzer, 2002). One study that attempted to explore the link between knowledge and self-poured drinks found undergraduate students lacked knowledge of standard drink volumes,

over-poured drinks and underestimated consumption (White et al., 2005). This is of importance when considering data reported in surveys that ask about people's self-reported drinking patterns, and actual alcohol consumption is likely to be higher than reported (White et al., 2005). Therefore, even if people are aware of concepts like units and daily benchmarks, this does not mean they have the knowledge, or even the motivation, to translate this into actual health-promoting behaviours.

Knowledge of the harmful risks associated with alcohol

Young people appear to have a good understanding of the risks associated with alcohol, including harm to health, links with crime and other risky behaviours. Yet such knowledge does not necessarily act as disincentive to drink (Hanekom, 2004). Even very young children are aware that alcohol is bad for you and can make you sick, although specific knowledge of the long-term health effects of alcohol may develop with age (Huetteman, Sarvela and Benson, 1992; Sigelman et al., 2000).

Sigelman et al. (2000) used open-ended questions with children aged 6 to 12 years to explore their understanding of the long-term consequences of alcohol use. Although many of the children discussed how alcohol can cause general body damage and death (57% and 37%, respectively), only 26% of children mentioned effects to the heart and 27% mentioned brain damage. Very few of the children demonstrated awareness that long term alcohol use can damage the liver (3%) or cause pathological effects or violence (5%). In the same study, structured questions revealed that children often could not discriminate the effects of one drug from another (i.e. cocaine and alcohol) and tended to over generalise from their knowledge of more familiar drugs, such tobacco, to less familiar substances. There was greater differentiation between drug effects with age, in particular misconceptions about the effects produced by a given drug decreased, rather than an increase in accurate knowledge.

Research that has been guided by Piagetian theory has explored the complexity of children's reasoning about the effects of drinking, showing it to increase with age (Davies et al., 2004; Lieberman et al., 1992; Meltzer, Bibace and Walsh, 1984; Sigelman et al., 1999). For instance, younger children tend to focus on concrete and observable events, whereas older children were

able to give specific physiological explanations as to how drug effects occurred and also mentioned more unobservable bodily processes.

It has been suggested that it is not until adolescence that individuals can understand interacting casual factors within the body (Davies et al., 2004). Davies et al. (2004) investigated children's intuitive theories of alcohol and cocaine action (see section 2.1.1.1). They examined whether children aged from 6 to 8 and 11 to 12 years had a causal explanatory framework for the behavioural effects of drugs; "a causal explanatory framework would describe how an ingested drug alters an aspect of bodily functioning (or some other mediator of the drug's behavioural effect) and how change in the mediator(s) in turn causes change in behaviour (e.g., staggering)". They found that older students were better than younger individuals at moving beyond just describing cause-effect links to explaining them. For example, the majority of participants were able to name an intermediate factor or mediator between drug ingestion and behavioural outcome, for example the brain or the lungs (72% of 6 to 8 year olds and 87% of 11 to 12 year olds). More of the older group were able to describe how a drug causes a change through damaging brain cells (48% of 6 to 8 year olds and 70% of 11 to 12 year olds). Therefore, with regard to ability to provide a causal explanation for how alcohol affects behaviour, this increased with age. The authors argued that this pattern of results is consistent with the idea that knowledge of different body parts and of integrated physiological systems increases with age. However, Davies et al. (2004) argued that it is not necessary to have a sophisticated biological understanding of the effects of alcohol for children to reason theoretically about the about how drugs effect behaviour. Biological theories might not be relevant to some children's understanding about the effects of alcohol, and by understanding their own theories, it might be possible develop more effective health education interventions.

It is important to note that studies have also found that a substantial proportion of children and young people do *not* view alcohol as harmful. Porter-Serviss, Opheim and Hindmarsh (1994) reported that 23% of fourth to sixth grade children (ages 9 to 12 years) in their sample were unaware that beer is harmful. Furthermore, in relation to other substances (i.e. caffeine, glue sniffing or any illegal drugs) 15-16 year olds in one study evaluated alcohol as the least harmful (Turtle, Jones and Hickman, 1997). Alcohol is widely accepted in our society, for example it is used for socialising, relaxation and celebrations. In addition, it is frequently

portrayed in the media as glamorous, cool and sexy. Therefore as children have contact and become familiar with alcohol from a young age this may lead to a low assessment of the potential harm it can cause compared to other drugs. Moreover, older children and adolescents may minimise or ignore the negative consequences of their behaviour when drinking alcohol or engaging in other risky behaviours (Gerrard et al., 2008), to deal with the contradictions between what they know about the effect of alcohol's on health and their actual behaviour. The patterns of drinking behaviour, as explored in section 1.3.2.1 (i.e. at weekends) seems to suggest that alcohol is mainly used for social functions. To understand alcohol related behaviours we need to go beyond a simple exploration of knowledge to taking into account the social context and the social functions that alcohol supports. This is discussed further in chapter 4.

2.3.2.2 Alcohol Knowledge and Understanding in People with Disabilities

Compared to the general population, there have been few published studies exploring alcohol related knowledge in adults or young people with intellectual or physical disabilities. Where data is available, assessing knowledge is not usually the primarily objective of the study but is obtained from a few additional questions attached onto to questionnaires exploring alcohol related behaviour. For example, in a study examining drinking patterns of 55 Scottish adults with a mild to moderate intellectual disability Lawrenson et al. (1995) asked participants “do you think alcohol will ever harm you/ make you ill?”. A third of the men and women knew that alcohol could cause harm, but none could be specific about the types of problems alcohol might cause.

McCusker, Clare et al., (1993) compared alcohol knowledge across five groups of adults and young people. They included adults with mild intellectual disabilities staying in short term hospital accommodation for challenging behaviour (*n*16, aged 18 to 45 years); adults with mild intellectual disabilities living in the community (*n*21, aged 21 to 45 years); males staying at a special hospital unit (*n*10, aged 23 to 52); teenagers attending school (*n*22, aged from 14 to 17 years) and adults from a university population (*n*30, aged 24 to 40 years). A structured interview using a true/false format was used to elicit knowledge about alcohol. Questionnaire items covered whether or not alcohol was a drug or addictive, safe drinking practices and the

harmful effects of alcohol. Alcohol knowledge was lowest in two disability groups, with even the teenagers achieving higher scores. However, the non-disabled men from the special hospital unit also had low relatively low levels of knowledge. Descriptive analysis of the data revealed that many of the adults with a mild intellectual disability were aware of the various physical and mental problems that alcohol could cause. However, they were less knowledgeable about the safe limits of alcohol use and the relative strength of different drinks. They were also unaware that women are less tolerant to the effects of alcohol than men, and that alcohol is a drug, which is addictive. Myths, such as coffee and fresh air can help someone sober up, were also endorsed more by the participants with intellectual disabilities. In another study, Jobling and Cuskelly (2006) developed the Health Knowledge and Behaviour Interview (HKBI) to explore health knowledge and health behaviour in 11 to 18 year olds with Down syndrome living in Australia (see section 1.3.1.3). Participants were asked if there were any problems associated with alcohol use and only one person answered correctly. Thus from the limited available evidence, people with intellectual disabilities would seem to have very limited knowledge of alcohol use.

The literature exploring alcohol related knowledge in young people with disabilities is very sparse. This in itself is noteworthy, as it suggests that young people with intellectual disabilities may not be expected to enter the same adult world as their peers, or share the same social aspirations. The evidence in the previous chapter did indicate that fewer people with intellectual disabilities consume alcohol. Nevertheless, there was also a suggestion that a higher proportion of those that do consume alcohol do so to excess. Therefore, whilst knowledge alone cannot predict behaviour, it is important that young people are well informed about alcohol use, to help them to make safe and informed decisions.

2.3.3 Knowledge of Contraception, Reproduction and Sexually Transmitted Infections

2.3.3.1 Sexual Knowledge and Young People without Disabilities

Young people in Scotland are becoming sexually active at a younger age. Moreover, this is often associated with feelings of regret and unintended or unwanted pregnancies (Scottish

Executive, 2003b). To ensure these individuals are safe and to able to make informed decisions with regards to their sexuality, they need to be provided with education and information including knowledge of support services and how to access them (Winn et al., 1995). Winn et al., argue that understanding what young people know about sexual health is essential for the formulation and development of appropriate educational programmes. Evidence suggests that school-based sex and relationships (SRE) education can be effective in increasing understanding and changing attitudes, as well as having more concrete outcomes such as delayed initiation of sexual activity and reduced conception rates (Scottish Executive, 2003b). SRE programmes include information about delaying sexuality activity, contraceptive advice and work on inter-personal skills to help negotiate relationship difficulties. Such programmes have proved effective at delaying intercourse, and young people report having fewer partners and increased use of contraception. Unfortunately, research exploring young people's sexual health knowledge is limited and out-dated, with studies relying on small and unrepresentative sample sizes and employing a variety of measures that have often not been validated.

There are many factors other than knowledge that influence behaviour. This is likely to be truer for sexual health than any other health areas. Sexual relationships inevitably involve more than one person and are therefore inter-personal and involve negotiation skills. In addition, the highly emotionally charged nature of sex makes it harder for individuals to make rational decisions as they might regarding other aspects of their behaviour. It is also important to take into account the broader social context of sexual behaviour, which goes beyond the individual or even the interaction between two individuals. This context includes the powerful social and cultural norms relating to sexual behaviour, and the power relations between men and women (Ogden, 2007). Of course, at the same time, sexual activity itself is also a private act, thereby making it intensely personal. Interestingly, there is evidence of a discrepancy between knowledge and actual behaviour in the area of sexual health and for the limited effectiveness of health education strategies (Goldmeier and Richardson, 2005).

Nevertheless, there are aspects of sexual health that knowledge can make an important contribution to. For example, for young people to be able to make decisions about contraceptives and to be able to use them effectively, they require a basic understanding of

their bodies and how contraceptives work. Hockenberry-Eaton et al. (1996) interviewed 90 adolescents (aged 13 to 15 years) and 73 mothers of adolescents. Participants were asked to define seven terms related to sexual development. Sixty-four percent of the sample gave a correct definition of menstruation, 52% for semen, and 42% for ejaculation, 17 % for wet dreams, 7% for hormones, 29% for ovulation and 37% for puberty. Although in general females outperformed their male counterparts, it seemed that many of the adolescents in this sample were unable to adequately define many terms relating to sexual development. However, this study failed to take into account the fact that young people have their own language and way of thinking with regard to sexual health. Young people often do not know and understand the terminology used by physicians with regard to sexuality, but will use their own language or colloquial speech (Ammerman, Perelli et al., 1992). Therefore this study may have failed to accurately access young people's understandings or misunderstandings about sexual development, and in turn provide little insight into how sex education strategies may be better delivered. Another finding reported in this study was that, although mothers gave the least number of incorrect definitions, they were still not able define most of the terms. Consequently, the authors argued that many of the mothers may have been ill-equipped to teach their children about sex or reinforce information their children learned in school.

Winn et al., (1995) assessed knowledge about puberty and sexual development in young people aged between 11 and 14 years. They reported that knowledge increased more between ages 11-14 than between ages 14-16, although there was considerable variation between topics. Knowledge about contraception and STIs tended to be gained in the later years. Girls tended to be more knowledgeable than boys across ages, a finding that has been reported elsewhere and particularly in relation to contraception and STIs; this gender-knowledge gap also appears to increase with age (Winn et al., 1995). Winn et al., noted that even amongst 15 and 16 year olds there were many misunderstandings, including not knowing that using oil-based lubricants can affect the effectiveness of a condom, that the pill is the most effective method of contraception, or that a woman can still get pregnant if she has sex standing up. Other studies have also reported young people to have misunderstandings around puberty and sexual development (Cumming et al., 1991; Phelps, Mellanby and Tripp, 1992). Cumming, Cumming and Kieren (1991) reviewed the literature on menstrual mythology in young people,

arguing that young people's knowledge of reproductive physiology is inadequate and is full of superstitions, illogical beliefs and misconceptions and that overall knowledge is inadequate.

More recently a survey was conducted with 15 year olds in Scotland, exploring attitudes to condoms and the use of contraception (Todd, Currie and Smith, 1999). Most of the 1727 young people interviewed knew that condoms are effective in preventing infections during sexual intercourse (83.4 % of males and 85.7% of females) and in preventing pregnancy (90.5% of males and 83.4% of females). The majority also agreed that condoms were easy to obtain (82.5% of males and 77.4% of females) and easy to use (80.5% of males and 65.6% of females). However, the drawback with this study is that young people were asked to say whether they agreed or disagreed with various statements (i.e. "condoms are easy to use"). Unfortunately this provides little insight into young people's understanding of how contraceptives should be used or how they work, and it is likely that the participants' knowledge was overestimated and misconceptions overlooked. Nevertheless, such a questioning style can be useful in topics of a sensitive nature, like sexual health, which individuals may find difficult to discuss. However they tell us little about people's understanding and thinking in relation to such topics.

Misunderstandings and misplaced concerns about the negative consequences of using contraceptives have been found in several studies (Oddens et al., 1994; Tessler and Peipert, 1997). A survey that was conducted in England, Scotland and Wales reported that adolescents and women associated serious side effects and health risks such as cardiovascular disease (45%), cancer (41%), and weight gain (73%) with oral contraceptives (Oddens et al., 1994). What the above studies suggest is that young people and adults hold many negative beliefs towards oral contraceptives, and this may have an impact on their use (Oddens et al., 1994).

Young people also appear to have limited knowledge regarding sexually transmitted infections (Garside et al., 2001; Westwood and Mullan, 2006). Garside et al. (2001) used both quantitative and qualitative methods to explore young people's (aged 13 to 16 years) knowledge of sexually transmitted infections (STIs). Overall, young people were not well informed about STIs, with two-thirds not having heard of chlamydia. Even if participants could name specific STIs they remained confused over how they could tell if they had one,

with one quarter of the sample being unaware that sometimes STIs are asymptomatic. The young people in this study also viewed condoms primary as a method of contraception rather than protection against infection. This coincides with other research suggesting that adolescents are more concerned about pregnancy prevention than they are disease prevention (De Visser, 2005; Whaley, 1999). In Garside et al's study, girls perceived enhancing the sexual encounter such as making their partner feel special, to be more important than pregnancy or disease avoidance. In addition, girls in this study tended to rely on *post hoc* contraception, such as the morning after pill, again highlighting their concern with avoiding pregnancy.

It therefore appears that young people have many gaps in their knowledge in relation to reproduction, contraception, and STIs, as well as holding many negative beliefs about contraception. To make this situation worse, many studies have also reported that young people lack information regarding sexual health services. For example, a Scottish sample of 14 to 16 year olds, 73% of girls but only 52% of boys were aware of the sexual health services available to them (Salihi et al., 2002). These young people also desired further information on topics such as sexually transmitted diseases, safe sex and having a baby. Furthermore, 33% believed that they had received too little sex education at school, 32% stated that they had received no sex education at home, and 10% said that they had had 'too little' sex education. Similarly, in the English study by Garside et al. (2001) cited above, less than half of the young people knew where they could get free condoms from and few were aware of genitourinary medicine clinics. Reeves et al. (2006) interviewed three-hundred and sixty young people aged 15 to 16 years attending secondary schools in the UK about their perceptions of sexual health services and education. They reported that more than one-third of the young people interviewed did not know that under 16s could buy condoms, nearly half were unaware that it is against the law for a girl to have sex with a boy who is under 16, and only half of the sample believed that a girl under 16 can obtain the pill without parental consent.

Young people seem to be more knowledgeable about HIV and AIDS than they are other STIs (Garside et al., 2001). For example, the British Market Research Bureau (BMRB) tracking survey (2003) reported that 96% of young people were aware of HIV/AIDS, whereas only two thirds of their sample had heard of genital warts, hepatitis, syphilis, gonorrhoea or chlamydia.

This may be related the high media attention of AIDS in comparison to other sexually transmitted diseases.

Nonetheless, a survey carried out in Scotland reported that, although 15 year olds had a good knowledge of key risk factors for HIV infection, they also had misconceptions (Todd, Currie and Smith, 1999). The majority of students knew that HIV is transmitted through sharing needles (96.2%) and unprotected sexual intercourse (95%). In addition they knew that condoms can help protect against HIV infection (92%) and that having many sexual partners increases the risk of contracting HIV (90%). A substantial proportion of the sample surveyed also knew that HIV cannot be transmitted through kissing (81%) and that a pregnant woman who has become infected with HIV can pass it on to her baby (73%). However, there were misconceptions with regard to understanding the diagnosis and treatment of HIV/AIDS. Although 84% knew the only way to tell if someone has HIV is through a blood test, just under half (46%) thought that AIDS can be cured if diagnosed early enough. A further 53% thought that there was a vaccine available in Scotland to prevent people becoming infected with HIV. However, as stated earlier, this study asked participants to say whether they agreed with or disagreed with a statement. There was no attempt to explore their reasoning behind their responses and this is likely to have inflated the knowledge scores.

It is important to note that the survey carried out by Todd, Currie and Smith was in the late 1990's, when the impact of the AIDs epidemic was fresh in people's minds. A more recent survey of 142,281 young people living in the UK conducted by the Schools Health Education Unit (SHEU; 2004) reported a decline in the knowledge of 12 to 15 year olds about the dangers of HIV/AIDS. For example, in 1995, 77% of males and 81% of females aged 12 to 13 years believed that HIV could be passed on through unprotected sex. This decreased to 63% and 66% in 2001. The corresponding figures for young people aged 14 to 15 were 89% for males and 93% for females in 1995, and 80% for males and 84% for females in 2001. Similarly, with regard to sharing needles, 74% and 82% of males and females aged 12 to 13 years knew this was a high-risk behaviour in 1995, but only 58% and 59% did in 2001. For young people aged 14 to 15 years, 90% of males and 93% of females knew sharing needles was risky in 1995, but only 77% of males and 81% of females did in 2001. For low risk behaviours, such as drug taking (other than needles), kissing, using public toilets and touching,

although few participants endorsed these, the numbers who did appear to have increased from 1995 to 2001. Overall, females had better knowledge than their male counterparts.

Adults and young people frequently do not perceive themselves to be personally at risk of contracting HIV, frequently associating this disease with certain at 'risk groups', i.e. drug users or adults (Palmer, Boardman and Bauchner, 1996; Wight, 1993). In addition to this, condom use appears to be inconsistent and when condoms are used, frequently their primary function is pregnancy prevention rather than the prevention of infection (Garside et al., 2001). With regards to knowledge of HIV, although individuals appear to have a clear idea of the main routes of HIV transmission, difficulties arise with understanding how HIV is not transmitted, i.e. through casual contact. This finding is important for two main reasons. Firstly, such misconceptions can lead to unnecessary fear and distress in individuals, as well as increasing stigma towards people with HIV. If greater stigma is attached to having HIV, people will be less inclined to undergo HIV tests. In turn, this will increase the number of undiagnosed infected people in the population and rates of HIV infection will continue to rise. Secondly, as people's knowledge of HIV is laden with misconceptions this would suggest that knowledge is largely superficial, with people lacking the necessary understanding to refute myths. People may have picked up on key health messages with regards to possible routes of HIV transmission, many of which they identify in response to the structured questions frequently employed by large scale surveys. However, large-scale surveys and structured questionnaire formats tell us little about why and how people come to have these misconceptions and consequently how best they can be challenged.

Sigelman et al. (1996) attempted to characterise children's intuitive theories of AIDS transmission using cluster analysis. One hundred and eighty-eight children and adolescents aged from 6 years to 18 years responded to a list of 32 behaviours, and rated how likely they thought the behaviours could lead to AIDS (i.e. 'no chance' to 'big chance'). With increasing age there was a sharper differentiation between true risk factors and false risk factors, with true risks being more strongly endorsed and false ones more decisively rejected. Six to eight year olds were significantly less likely than any other age group to endorse drug use and sex as causes of HIV and significantly more likely to state that it can be transmitted through the air, through contact with someone who has AIDS, low risk drug (i.e. smoking marijuana, drinking

alcohol) and low risk contacts with blood (mosquito or donating blood). Across all ages many children and young people held saliva exchange and blood-related myths. Cluster analysis was then applied to the responses and three relatively immature theories and two relatively mature ones were identified, described in table 2.1. There was a gradual shift from the three immature theories (theories 1-3 in the table) towards more accurate theories 4 and 5.

Table 2.1: Intuitive Theories of Human Immunodeficiency Virus Transmission adapted from Sigelman et al. (1996)

Theory	Mean Age	Description
1. Undifferentiated Thinking	8.4	Participants were average in their endorsement of true risk factors but had many misconceptions. Endorsed magical thinking (i.e. stealing or lying can cause AIDS). Believed almost anything could cause AIDS
2. Reject True/No Clue	9.2	Least likely to view true AIDS risk factors as causes of AIDS. No strong intuitions about what causes AIDS and responded very tentatively to the risk factor items.
3. Germs and Drugs	8.7	Drug use of any sort and behaviours that cause colds cause AIDS. Seem to have constructed a hybrid theory blending a germ theory of disease and newly acquired but overgeneralised knowledge about the dangers of sharing drug needles.
4. True Risks/Not Blood	13.6	Relatively accurate view of HIV transmission. Sex and drug needle sharing were seen as cause of AIDS, they firmly rejected most myths, but were sceptical about AIDS being caused by contact with the blood of someone with AIDS
5. True Risks/Blood Myths	13.6	Basically correct view of AIDS causality, but more strongly endorsed true risk factors and less decisive rejection of non-risky blood contacts. Knew messages about dangers of blood more than Cluster 4, but had overgeneralised these messages.

The authors concluded that younger children start with theories where virtually anything causes AIDS, and are unsure of its causes or believe it is very hard to catch, or they apply a variant of a germ theory. Later they tend to endorse a germ theory, onto which they graft beliefs about the risk factors for catching AIDS. With further development, they are able to differentiate more sharply between true risk factors and behaviours that superficially resemble these, probably through the understanding of internalisation of virus through blood exchange and sexual fluids. Again, it appears that with age children move from undifferentiated theories, frequently relying on other theories that already have (i.e. germ theory for colds) and with more knowledge these theories become more differentiated or even new theories. However,

the authors acknowledge that the cluster analysis is quite subjective and the sample size in their study was small.

In another study investigating the development of young people's understanding of HIV, Keselman et al., (2004) explored the nature and organisation of HIV knowledge in 21 adolescents from grades 7, 9 and 12 (ages 12-13 and 14-18 years, respectively). They argued that a certain level of conceptual biological knowledge is required for decision making in relation to health. For example, if an individual has a greater understanding of the biological mechanisms involved in HIV they will be more likely to reject myths. In their study they used both a semi-structured interview to explore understanding of HIV and a reasoning task, where participants were presented with myths about HIV. In order to reject these myths, they had to understand and be able to apply certain biological concepts. From the responses to the semi-structured interview, the authors characterised the participants' understanding of HIV into three models: naive, intermediate and advanced. The key findings for each of these models in are presented in table 2.2.

With regards to reasoning, responses were coded into three levels of biological reasoning: cellular level (discuss structures and processes at or below the cellular level, i.e. white blood cells, replication), system level (discuss specific organs or structures of the body, bodily fluids and processes) and non-specific (structures and processes that are only biological in the general sense (e.g. body, diseases) and are non-scientific, commonsense notions). There was a clear association between level of understanding and ability to reject myths. For example, whereas advanced model students drew upon their knowledge to refute myths, the naive and intermediate students' knowledge was too 'brittle to challenge the myths' even if it was inconsistent with what they thought or their experiences. Naive and intermediate students also overgeneralised from their existing knowledge (i.e. of other illnesses).

There may be criticisms of Keselman et al.'s (2004) study, including the small sample size and the attempt to synthesise a range of complex material into three distinct models. Nevertheless, in common with the other studies which have been considered, they demonstrate that as young people develop cognitively, and with increasing knowledge, they obtain a better grasp of conditions like HIV. Of course, having an understanding of underlying biological

mechanisms might not shift ingrained social prejudice towards people with HIV, or that sexual behaviour is not driven by other motivating factors than health knowledge. These issues will be addressed in a later chapter. However, the link between cognitive development and an understanding of sexual issues has implications for people with intellectual disabilities.

Table 2.2: Models of HIV Understanding (Keselman et al., 2004)

Models of HIV Understanding	Description
Naive Model - Level (9 middle and 2 high school students)	<p>Core concept of HIV: No understanding of the concepts of virus, infection, and immune system.</p> <p>Mechanism of HIV Infection: No common theme that would unite different routes of HIV transmission (i.e. bodily fluids). They knew that HIV was associated with sex and a few older participants mentioned drugs and the exchange of blood. Without understanding bodily fluids as common route of transmission, had a poor understanding of how protection (i.e. condoms work). Lack of understanding of how HIV is transmitted led to misconceptions such as once you stop having sex, you will get better. As didn't understand the concept of virus, they had to find another casual agent for HIV transmission, for example dirt, leading to misconceptions about the role of personal hygiene in transmitting HIV.</p> <p>Disease Progression: Without the relevant biological concepts, they did not know what happens to the body or the connection between HIV and AIDS (frequently HIV and AIDS were referred to as different diseases)</p>
Intermediate Model - Level (7 students, mainly high school)	<p>Core concept of HIV: although could not describe the viral structure or life cycle, they knew HIV was a virus.</p> <p>Mechanism of HIV Infection: As they understood that HIV is transmitted through fluids, they were able to link various routes of HIV transmission; "you get it through blood transfusion, which includes birth, and drugs, and unprotected sex".</p> <p>Disease Progression: They understood that HIV it affects the immune system and destroys the body's ability to fight disease. They understood that AIDS was the end stage of HIV infection. Their understanding was sufficiently biologically grounded to enable them to organise facts about HIV, and as such did not share the same misconceptions as the naive model participants.</p>
Advanced Model - Level (3 students, all high school)	<p>Core concept of HIV: Participants understood HIV to be a virus that contains genetic material in order for it to replicate inside the host.</p> <p>Mechanism of HIV Infection: They knew it enters the body through transmission of fluids and enters white blood cells where it can replicates and eventually destroys them.</p> <p>Disease Progression: As the viral cells increases and the white bloods cell decrease, the body is unable to fight off opportunistic diseases.</p>

2.3.3.2 Sexual Knowledge and Young People with Intellectual and Physical Disabilities

What has become apparent in the literature discussed hitherto is the large variance in terms of both quantity and quality of research seen across health topics. Young people's healthy eating

and alcohol-related behaviours and knowledge have attracted substantial interest from researchers and policy makers, with the aim of understanding and changing individuals' attitudes and behaviour. In contrast, research exploring sexual health issues has been more limited and inconsistent. This division becomes even more striking when people with disabilities are the focus of the research. There has been relatively little research conducted with adults with intellectual disabilities in relation to sexuality, let alone with children and adolescents. Yet sexual education is a life-long process; children acquire information and form attitudes, beliefs and values from a young age, not only through the direct impartment of information, but also through their own observations and interactions with others (Cole and Cole, 1993). Sexual education therefore needs to begin at a young age to help normalise sexuality and, in turn, help young people to develop a healthy and positive sexuality.

One explanation for the discrepancy between research conducted across these different health areas is that sex and sexuality are considered very much 'private issues' (Richardson, 2000). Shakespeare (2000) has highlighted that it is easier to discuss and tackle issues of physical access and discrimination than it is to address exclusion from sexuality. Shakespeare claimed that although the personal challenges that people with disabilities face, which include general health, have been made into 'public issues', "the private lives of disabled women and men were not seen as being equally worthy of concern" (Shakespeare, 2000. p.160). This reflects the negative attitudes still prevalent in wider society about the sexuality of people with intellectual disabilities, who can be seen and treated as asexual and child-like at one extreme and sexually deviant at the other (Ailey et al., 2003). In turn, this had led to a situation where "education and support around sexuality, sexual health and personal relationships has tended to be avoided or ignored" (Simpson et al., 2006, p.12).

It was argued earlier that comprehensive sex education can be effective at assisting young people in making healthy decisions about sex and adopting healthy sexual behaviours. However, there is a lack of consistency in providing Sex and Relationship Education to young people with intellectual disabilities and the effectiveness of different approaches have not been evaluated (Fraser and Sim, 2007). Investigating young people with intellectual disabilities' knowledge and attitudes towards sex is therefore essential for the designing and evaluation of such programmes (Winn et al., 1995).

In an early study, Edmonson, McCombs and Wish (1979) compared the sexual knowledge and attitudes of people with moderate and severe intellectual disabilities, using a tool known as the Socio-Sexual Knowledge and Attitude Test (SSKAT; Wish, McCombs, and Edmondson, 1979). They reported that participants had a poor understanding of birth control, homosexuality and sexually transmitted diseases. Moreover, although sexual knowledge was associated with participants' IQ scores, the authors reported that living situation (institutionalised versus non-institutionalised) and gender were larger determinants of knowledge. More recent studies have also reported, perhaps not surprisingly, that adults with an intellectual disability score consistently lower in most areas of sexual knowledge than their non-disabled peers (McCabe, 1999; Szolios and McCabe, 1995). Szolios and McCabe (1995) explored the sexual knowledge and experiences of 25 adults with mild intellectual disability relocated from institutions. The participants had been living in the community for at least five years. Using individual interviews, sexual knowledge was compared with that of 39 first year university students without a disability. Participants with disabilities were best at identifying body parts, although they were not as good at describing functions of body parts with a sexual purpose, such as the breasts and the vagina. Although approximately half of the participants answered questions about contraception correctly, their knowledge of STDs was low. Compared to the non-disabled students, participants with intellectual disabilities' knowledge was low, with the exception of menstruation and identifying body parts. In addition, participants had held many myths, including the belief that women give birth without being pregnant, that masturbation can cause harm, men have periods, and during sexual intercourse the penis enters the female's anus. As with findings from the general population, females were more knowledgeable than males about sexual matters (Szolios and McCabe, 1995).

Galea et al. (2004) assessed sexual knowledge in 96 community-dwelling Australian adults with intellectual disabilities, the majority (75%) of whom had a mild intellectual disability. Using an instrument known as the Assessment of Sexual Knowledge (ASK), the authors found sexual knowledge to be poor, particularly in relation to sexually transmitted infections, sexual health, safer sex practices, legal issues and contraception, although there was a high degree of variability between participants. Siebelink et al. (2006) developed a questionnaire exploring sexual knowledge, attitudes and experience in 76 people with mild to moderate learning disabilities, aged 18 and over. Although the questionnaire was very limited (two yes/no

questions on possible consequences of sexual intercourse (pregnancy and STDs) and two open-ended questions on condoms and masturbation (what is happening in this picture?), the authors found an association between greater levels of knowledge and more positive attitudes towards sex, which in turn were associated with greater experience.

McCarthy's in-depth work concerning women with intellectual disabilities in the UK (McCarthy, 2009a, 2009b) described in chapter 1 illustrated how the majority of women she interview had little knowledge of what contraception was or how it worked. In addition, the participants had a poor understanding of reproduction, the menopause, or the link between fertility and the need for contraception. None of the women were given any accessible information about contraception, despite this being desired. Similarly, several women in the study by Szolios and McCabe (1995) were unsure of the function of their contraceptive pill, with the most common response being that it had "something to do with their periods" (p. 218). This suggests that contraception for these women had little to do with sexual rights and more to do with protection and control.

Cheng and Udry (2003) explored knowledge of birth control in 15 to 18 year olds with and without intellectual disabilities living in the USA. The sample consisted of 8775 boys and 9158 girls, of which only a small percentage had an intellectual disability (mild disability: 1.7% and severe disability: 0.8%). Although the young people with intellectual disabilities appeared to have poorer knowledge about birth control and fertility than their non-disabled peers, some of the questions used to assess this were problematic. For example, participants were asked to respond to questions such as "most women's periods are regular, that is they ovulate (are fertile) fourteen days after their periods begin". It is likely that most people with intellectual disabilities would find questions of this nature and the abstract concepts they refer to difficult to understand.

People with physical disabilities, like their peers with intellectual disabilities, have long been subject to negative societal attitudes towards their sexuality (Di Giulio, 2003). McCabe (1999) investigated the sexual knowledge, feelings, experience, and needs of 60 people with mild intellectual disabilities compared to those of people with physical disabilities and people from the general population, using the Sexual Knowledge, Experience and Needs Scale (SexKen).

In all areas of sexuality assessed she found that the participants with intellectual disabilities demonstrated lower levels of knowledge than the participants with physical disabilities, who in turn demonstrated lower levels of knowledge than the participants from the general population. Interestingly, participants with intellectual and physical disabilities were less likely to discuss sexual matters with their family or friends than non-disabled participants.

In addition, young people with physical disabilities may have unique concerns about sexual relationships, sexual function, and reproductive capacity. For example, Sawyer and Roberts (1999) explored the sexual and reproductive health knowledge, attitudes, and behaviour of young people, aged between 14 and 23 years, with spina bifida living in Australia. Although school was the primary source of sex education, only four out of the 51 young people interviewed reported that they had received adequate spina bifida specific sex education, with many young people and their parents rating their knowledge as 'poor' or 'extremely poor'. Many of the young people and their parents had potentially distressing gaps in their knowledge. For example, only 12 (18%) parents were aware that fertility in males with spina bifida is usually reduced, and 33 (65%) of young people believing a man with spina bifida could father a child. In relation to women, 23 (34%) of the parents were aware that females with spina bifida usually have normal fertility, and 41 (80%) of the young people believed that women with spina bifida could become pregnant. Although the authors reported that these young people had received adequate sex education, their specific knowledge of how their disability could affect their sexuality was poor.

Duh (2000) explored sexual knowledge between 104 visually impaired adolescents and 180 'healthy' controls in Taiwan. Knowledge of anatomy, puberty, contraception and STDs was lower for the adolescents with visual impairments than the control group, although all groups were least knowledgeable about STDs, followed by contraception. Both groups performed better with regards to anatomy and puberty.

2.4 Conclusion

Although over the last three decades research exploring sexual issues for people with disabilities has begun to accumulate, this is still limited, with studies relying on small sample sizes and rarely using control groups. Comparisons across studies are also confounded by factors such as living environments and level of disability. Many of the studies cited above have used validated measures to assess sexual knowledge, such as the SSKAT, ASK and SexKen. Although these tend to measure similar areas, differences in how questions are worded and how the questionnaire is administered can create disparities. In addition, all the questionnaires are very time consuming, which can be problematic for people with intellectual and physical disabilities, who may have problems with issues like concentration, fatigue and chronic pain. An example of this is seen with the SexKen which can take up to three, one-hour interviews to complete. Herein lies the difficulty with research exploring sexual knowledge and attitudes. It is an inherently complex and emotionally charged topic, and there is the concern that survey type measures may be reducing 'sexuality to a series of facts' (Winn et al., 1998, p.22). Hence such survey approaches do not necessarily capture people's understanding, which is contextual and rooted in their experience and life circumstances.

Despite a great deal of variability across studies, there is a fairly consistent finding that people with intellectual and physical disabilities appear to have lower levels of sexual knowledge than their non-disabled peers. The fact that for some areas of sexual knowledge the discrepancy between people with and without disabilities is greater, suggests that these young people may be being excluded from the opportunity to develop certain aspects of their sexual understanding or have greater difficulty accessing the necessary information or experience. This will be the focus of the next chapter.

Chapter 3: Social Exclusion and Young People with Disabilities

3.1 Introduction

In Chapter two the research exploring young people's knowledge about health, including alcohol, healthy eating and sexual health was reviewed. Two major themes became apparent. Firstly, knowledge does not always predict behaviour. Many of the young people without disabilities demonstrated high levels of knowledge in relation to health (although there were also many misunderstandings) but this did not deter them from engaging in health risking behaviours. Secondly, young people with disabilities demonstrated much lower levels of knowledge with respect to all these health areas compared to their non-disabled peers. This leaves us with two main questions. First, why do young people choose to engage in health risking behaviours, even when they are fully aware of the risks involved? And second, why do young people with disabilities have such low levels of knowledge? The first question will be dealt with in chapter 4, which explores young people's motivations for engaging in health-risking behaviours and focuses on research examining the role of social and contextual factors in people's experiences of health and illness. In the current chapter, research that may further our understanding of why young people with disabilities have low levels of knowledge in relation to health is reviewed.

3.2 Disability in Context

There has been an increasing recognition of the role of social and contextual factors when exploring young people's understanding of health and illness. However, for young people with intellectual disabilities, it is commonly assumed that maladaptive behaviour is due to their lack of understanding or awareness, a consequence of having a cognitive deficit. Although having a cognitive impairment is undoubtedly an important factor when considering health education, the emphasis is often so powerful that it overshadows the impact of experience. In the following discussion, the importance of the social context in understanding young people with disabilities' health knowledge, understanding and behaviour will be considered. Initially, a

definition of social exclusion will be outlined for the purposes of the current study. Evidence will then be presented illustrating how young people with intellectual and physical disabilities are more likely to experience social exclusion, which can impact upon their health knowledge and understanding, drawing upon the framework of Social Capital. Following this, evidence that young people with disabilities face other attitudinal and structural barriers preventing them from accessing the experiences and opportunities to learn about health as do their non-disabled peers will be reviewed. This review will focus mainly upon research from the area of sexuality as this is an area that people with disabilities have historically been excluded from.

3.3 Definitions of Social Exclusion

As discussed in chapter 1.2., people with intellectual disabilities are among one of the most socially disadvantaged groups of people within society. Although social exclusion has emerged as an important concept in discussions about disadvantage, defining social exclusion can be problematic as it is a contested and complex concept (Morgan et al., 2007). The definition provided by the Social Exclusion Unit (SEU) suggests that:

‘Social exclusion is about more than income poverty. Social exclusion happens when people or places suffer from a series of problems such as unemployment, discrimination, poor skills, low incomes, poor housing, high crime, ill health and family breakdown. When such problems combine they can create a vicious circle.’ (SEU, 2006).

Thus it is clear that social exclusion can cover a range of factors that can work together to prevent individuals from participating in the normal activities of society that the great majority of non-disabled people enjoy. Burchardt, Le Grand and Piachaud (1999) define ‘normal activities’ as having “a reasonable living standard, to possess a degree of security, to be engaged in an activity which is valued by others, to have some decision-making power, and to be able to draw support from immediate family, friends and a wider community” (p231).

From the preceding chapters, it has been highlighted that young people with disabilities may be excluded from the opportunity to develop certain aspects of their health understanding, in particular in relation to sexual matters. This may stem from having greater difficulty accessing information or experience and their limited opportunities to exercise control over their lives.

Thus, for the purposes of this study, the key features of social exclusion that will be explored are in terms of impoverished social networks, such as limited friends and community involvement, decreased autonomy and decision making opportunities, and reduced access to services and resources. These factors are discussed in greater detail below.

3.4 Social Capital and Health

Social capital is an area of research that has explored the importance of bringing together both individual psychology and sociological approaches in shaping individual and community behaviour. There are many definitions of social capital, although these tend to overlap (De Silva et al., 2005) and within the social sciences the emphasis is on the role of informal and formal networks and civic norms (ONS, 2001). Putnam (2000) defined social capital as the connections amongst individuals, and the social networks and the norms of reciprocity and trust that arise from them. There is no widely held consensus about how to measure social capital, however, key constructs include social relationships and networks, group membership and local identity and shared norms and trust (Swann and Morgan, 2002). Involvement in community life is a central construct in social capital, with the percentage of people belonging to community based organisations (i.e. choirs, sports clubs, charities) being considered the most important.

Bourdieu, Coleman and Putnam are most commonly cited in contemporary discussions of social capital, although it was Robert Putnam who made popular the concept of social capital through his work exploring civic engagement in the United States and Italy (Putnam, 2000; Putnam, Leonardi, and Nanetti, 1993). In *Making Democracy Work*, Putnam et al. (1993) explored differences between regional governance in the north and south of Italy. He reported a close relationship between social capital and better quality of government performance. In Putnam's (2000) book - *Bowling Alone*, Putnam focused on the decline in civic engagement in the United States. He states that higher rates of community involvement had the smallest differences in income. He also suggested possible reasons for this decline or lack of social capital in some areas, including lack of time, poverty, disruption of family ties/structure, and changes in economic structure.

Social capital has been linked to better health (physical and psychological) and in improving the efficiency of societal institutions (Furstenberg and Hughes, 1995). In reviewing the evidence on social capital and inequality, Wilkinson (2005) demonstrated a close relationship between quality of social relations and inequalities in society. He discussed circumstantial evidence which indicated that more egalitarian societies are more socially cohesive, have lower rates of crime and higher levels of interpersonal trust (Wilkinson, 2005). High social capital has been correlated with various social outcomes, including lower rates of crime (Putnam 2000) improved health and longevity (Kawachi et al., 1997; Putnam, 2000), better educational achievement (Coleman, 1988), and more even distribution of wealth (Wilkinson 1996). Strong social support networks, particularly informal networks have been shown to have positive impacts on well being, by reducing isolation, helping people to feel valued and understood and providing practical and emotional support (Cohen and Syme, 1984; Cohen and Wills, 1985; Helliwell and Putman, 2004; Hughes 1999). Interacting with others can also help to raise our self-esteem and feelings of acceptance (Cohen and Wills, 1985; Firth and Rapley, 1990) and promote our physical and psychological well-being (Duck, 1991; Sarason et al., 1997; Marmot and Wilkinson, 1999; McVilly et al., 2006). Although formal support systems, such as those providing medical help, are essential, they only fulfil a minority of most people's support needs (Hamlin, 2004).

Putnam (2000) also discusses two distinct types of social capital: bonding and bridging. Bonding social capital results from relationships between similar persons, for example, those alike with respect to socio-demographic and socio-economic characteristics which may include friends, family, neighbours, and co-workers. Bridging social capital comprises relations with dissimilar persons and may span different communities. Whereas bonding social capital provides individuals with support and well-being in the present, bridging social capital means that people can draw on a broader range of social resources to face new challenges or to deal with novel situations (Morrow, 2002). As such, this is a potentially important distinction to make when reflecting on the social networks of socially marginalised groups at stages of change in their lives.

The importance of social capital for people with intellectual disabilities has long been recognised and these individuals have consistently voiced their need to develop friendships

and engage in social contexts that bind them to their communities (Cummins and Lau, 2003; Froese et al., 1999; Johnson 2000; Knox and Hickson, 2001). Recent policy has recognised the importance of fostering the participation of people with intellectual disabilities in their communities, acknowledging that children and adults with intellectual disabilities face many barriers to full participation in society (The Same as You, Scottish Executive, 2000; Valuing People, Department of Health, 2001).

“People with learning disabilities are amongst the most vulnerable and socially excluded in our society. Very few have jobs, live in their own homes or have choice over who cares for them. This needs to change: people with learning disabilities must no longer be marginalised or excluded” (Department of Health, 2001. p2).

Whilst acknowledging the importance of developing friendships, it has also been highlighted that “helping people sustain friendships is consistently shown as being one of the greatest challenges faced by intellectual disability services (Department of Health, 2001, p81).

There have been significant changes in residential services for individuals with intellectual disabilities, with a move away from residential care provision to providing smaller services supporting individuals in the community. One reason behind these changes has been the goal of promoting the social inclusion of people with intellectual disabilities within their local community and enhancing quality of life. Although individuals living in community-based residences have better social networks compared to those living in institutional settings (Heller 2002), many people with intellectual disabilities are still isolated and disempowered. For example, Forrester-Jones et al., (2006) examined the social networks of 213 adults with intellectual disabilities in the community 12 years after moving from hospital settings. The average size of social networks was 22 members (ranging from 3–51). However, social networks were largely made up of staff members (43%), followed by other people with intellectual disabilities (25%). Only a third of the members were unrelated to intellectual disability services, with on average 14% being family members, and 11% being friends and social acquaintances. Participants in this study had few opportunities to engage in community activities and very few participants were in any form of employment. Ager et al., (2001) examined levels of social integration for individuals resettling into the community, once again reporting a large bias towards contacts with staff and other service users. In addition, although

there was evidence of increased community presence, activities requiring a high degree of personal autonomy were infrequent. For example, few if any of those in the study had friends to stay overnight or to visit for a meal. Similar findings were reported by Emerson and McVilly (2004) in a large population-based study on adults with intellectual disability. Participants with intellectual disabilities had low levels of friendship activities, most being with friends who also have intellectual disabilities and took place in public places with little privacy. Robertson et al. (2001) explored the social networks of 500 adults with intellectual disabilities living in different types of residential supports. Participants had a median of only five network members (ranging from 0–20) and this was reduced to two people when staff contacts were excluded. Again, only 30% of the members of the participants' social networks were not relatives or individuals involved with intellectual disability services.

Variation in the size and composition of participants' social networks is associated with a range of variables, including age, adaptive and/or challenging behavior, living arrangements, staffing ratios and turnover (Emerson and McVilly, 2004; Forrester-Jones et al., 2004; McConkey, 2007; Robertson et al., 2001). For example non-long-stay patients have a greater number of community members in their social networks, suggesting residential history is an important factor in influencing social networks (Hatzidimitriadou and Forrester-Jones, 2002). With regard to living arrangements, in general, people living in smaller, supported living arrangements in the community have larger and more inclusive social networks than people in larger and residential settings (Emerson and McVilly, 2004; Forrester-Jones et al., 2006; McConkey, 2007; Robertson et al., 2001). Llewellyn and McConnell (2002) reported that mothers with learning disabilities had few supportive ties with friends and neighbours, meaning that many were isolated from their local communities. However social networks varied depending on where the mother lived. Those living at home with a parent had smaller networks mainly consisting of family members, whereas mothers living alone with their children had more widely dispersed family ties and relied heavily on formal service providers. Participants' social networks also consisted largely of staff and although these contacts provided information and advice, this support was not constant. In other words, relationships with individuals such as support workers tended to be short-term and infrequent. Abbott and McConkey (2006) conducted focus groups involving 68 people with intellectual disabilities who lived in supported living or shared group homes in Northern Ireland. Barriers to social

inclusion, as identified by participants, included personal abilities and skills, staff management of inclusion and whether the staff allowed and supported the individuals to go out. The location of the house within the community and access to transport also contributed to their autonomy. Finally, the community's attitudes, familiarity and how welcome they made individuals with intellectual disabilities also played a role in their inclusion or lack thereof.

Having a dense network, where a higher proportion of members within the social network are interconnected or known to one another (i.e. service users) can be problematic (Forrester-Jones et al., 2006). As discussed above, having ties with people from similar backgrounds (bonding social capital) can help people to get by in life by providing strong in-group loyalty and social support. This also raises the possibility of out-group antagonism, lack of privacy, corruption or exploitation (Cocks, 2002; Forrester-Jones et al., 2006). Having connections with people from different backgrounds and groups, or bridging social capital, can link an individual or community to resources and information, thereby helping them to 'get ahead' in life (ONS, 2008).

Researchers typically focused on the size and density of networks and friendships, yet fewer have asked participants what these networks mean to them. McVilly, Stancliffe, Parmenter and Burton-Smith (2006a) explored the construct of 'loneliness' as experienced by adults with intellectual disabilities, reporting that social and demographic factors did not satisfactorily explain participants' ratings of loneliness. For example, although lower ratings of loneliness were associated with spending more time with friends, there was no significant relationship between ratings of loneliness and size of social networks or frequency of contact with network members. For the loneliest participants, existing friendships were not always reciprocal (i.e. the other person did not take the relationship seriously) and failed to meet those participants' socio-emotional needs. Participants who reported being the least lonely did not rely upon a single member for their support, but were connected to a network of people that could meet a diversity of emotional and practical needs.

It appears that many individuals with intellectual disabilities living in the community are being denied the same social opportunities that most non-disabled people have access to. Even when social networks appear large this does not necessarily lead to social inclusion as they are made

up of predominately formal supports. In the general population, only a minority of support needs are fulfilled by these formal support systems (Hamlin, 2004), with friends and family providing different forms of support at different times in an individual's life (Llewellyn and McConnell, 2002). This suggests that many of the social and emotional needs of people with intellectual disabilities may not be being met.

3.5 Social Networks in Children and Young People with Disabilities

As with adult populations, children and young people with disabilities also have limited social networks. However, the development of social networks may be even more significant for adolescents. The changes associated with adolescence have been discussed in earlier chapters, but it is worth noting that adolescence is a period when young people strive to establish their own identities, independently from their families, through forging peer relationships. Friendships change during adolescence and the need for support from peers can become even more salient (Matheson, Olsen and Weisner, 2007). Issues around developing and sustaining friendships may be more evident for young people with disabilities.

Matheson et al., (2007) explored what friendships meant to American adolescents with disabilities. They reported that these adolescents' friendships tended to lack the depth of friendships reported by their typically developing peers. For example, for friendships to become deeper and sustainable the authors argue that they need to extend beyond the setting where they began. Hence, young people might be expected to meet school friends in the evenings and at weekends. Fifteen out of the 27 adolescents indicated that their friendships did generalise from one setting, however parents were heavily involved in facilitating these activities (i.e. transport, setting up meetings). This is in contrast to non-disabled adolescents who require little supervision to engage in activities with peers and frequently seek out such situations (Matheson et al., 2007). Activities that require a higher degree of personal autonomy are less frequently engaged in by adults with intellectual disabilities (Ager et al., 2001) suggesting that both adults and children with disabilities may need more support with these activities. In addition, as individuals with disabilities may attend schools far from their home, they may have fewer friends nearby to socialise with (Watson et al., 1999). The Scottish

Human Services Trust (SHS, 2002) conducted a participatory action research project involving 12 young people with intellectual disabilities living in Scotland. There were high levels of social isolation, with all of the participants reporting that they had little influence or control over who their friends were, where they could go, and when they could go out.

Children's friendships are initially based on proximity to peers, such as attending the same school, and sharing similar characteristics such as age, gender, and disability. With increasing age the wish to develop more intimate relationships means expectations of closeness and trust become increasingly salient for young people (Engels et al., 2007). However, Matheson et al., (2007) found that adolescents with disabilities continued to emphasise the importance of proximity and stability in maintaining friendships over time. This is perhaps not surprising, if school is the only opportunity that many of these individuals have to socialise with peers (SHS, 2002; Watson et al., 1999), and even within school young people are often segregated from their non-disabled peers in different classrooms (Gordon et al., 2004). In Watson's study, children with disabilities were frequently separated from other children. For example, during lunch period they were told where they should sit and with whom, with issues such as gender and race being ignored. Matheson et al. (2007) reported that companionship was the most frequently discussed feature of friendship with 22 of the 27 participants mentioning this. Although companionship is an important aspect of friendship, with increasing age other aspects such as trust, loyalty, and intimacy gain precedence, signifying a deeper and more mutual relationship. Few adolescents in this study talked about intimacy and disclosure when discussing their friendships and few discussed mutuality or reciprocity. The authors agreed that for these young people, relationships appeared to be less mature and intense compared to typically developing peers. While 17 out of the 27 adolescents made positive comments about their friendships, it would have been of interest to explore further how participants felt about their friendships.

It has been argued that families and carers do not always understand the importance that friendships have for people with intellectual disabilities and may not always prioritise this (McVilly et al., 2006b). Past research has highlighted a number of barriers to developing and sustaining friendships in the long term (McVilly et al., 2006b). Families' and professionals' attitudes may restrict people with intellectual disabilities from developing friendships and

relationships, for example by focusing on protection and risk instead of seeking opportunities for them to form relationships (Simpson, Lafferty and McConkey, 2006). The support young people require may include practical help, such as transport (McVilly et al., 2006b). As with adults, many young people with disabilities are also socially excluded in the community. Zetlin and Turner (1985) found that adolescents with intellectual disabilities experience high rates of peer rejection, while Cooney et al. (2006) reported that many of their participants had experienced bullying at school. In the Scottish study by SHS (2002), many of the young people interviewed had experienced neighbourhood harassment, such as verbal abuse and bullying on account of their disability. Of great importance to these young people was making new friends, yet such opportunities were very limited owing to poor ties with the community. They were not aware of group organisations, such as youth clubs and none had accessed mainstream leisure provisions (only a few had attended segregated ones). In part, this was due to staff being unaware how to support these young people with disabilities. As there was no help for them to access community leisure and social activities available to non-disabled young people, most of the group remained at home in their spare time. Young people with intellectual disabilities are more likely to engage in home based, solitary and passive activities with low levels of social interaction, mainly with other family members (Buttimer and Tierney, 2005). Research has suggested that adults form a disproportionately large part of their networks in comparison with their non-disabled peers (Buttimer et al., 2005; Cole and Cole, 1993; SHS, 2002; Watson et al., 1999). Watson et al. (1999) also reported that children and young people with disabilities spend much of their time in the company of adults or in contexts where adults were watching over them. This includes social as well as educational and vocational contexts.

Care should be taken when interpreting the findings of the studies discussed above due to small and unrepresentative sample sizes, such as in the studies by Buttimer et al. (2005) and the SHS (2002). In addition, most studies failed to include comparison groups and employed a variety of measures that had often not been validated. Perhaps more tellingly, the studies used different definitions of social inclusion, making it difficult to draw out common theoretical and practical strands.

Nevertheless, findings from these studies suggest that limited social networks and involvement in community life may lead to reduced access to activities where social skills can be practised, confidence gained, and meaningful relationships developed. For young people with disabilities, missing out on such opportunities and experiences may hinder the development of their sexual identity and intimate relationships in adulthood (Gordon et al., 2004; Howland and Rintala, 2001).

3.5.1 The Importance of Social Networks in Developing Sexuality

In seeking more intimate relationships, adolescents' interactions with their peers become intensified. At the same time they may be striving for greater independence (emotional, personal and financial) from their parents (Engels et al., 2007). Children and young people ascribe great importance to friendships, with the majority of their time and activities being based around peer groups (Morrow, 2002). These peer groups progress from mainly platonic friendships, often including 'cliques' or gangs, towards romantic relationships. Developing shared activities, and companionship can impact upon self-identity and esteem and lead to more meaningful, intimate relationships (Hartup and Stevens, 1999; SHS, 2002). However, for children and adolescents, informal and spontaneous interactions with peers also provide opportunities to develop social skills, adaptive behaviour and confidence, and enables them to learn peer norms and values (Cole and Cole, 1993; Hartup and Stevens, 1999). It is often during these interactions that sexual knowledge, language and attitudes are exchanged, and where individuals can observe, rehearse and experiment with sexual behaviour and gender roles (Cole and Cole, 1993; Gordon et al., 2004). However:

“Since most information about sex is learned quietly, covertly, and is greatly and dramatically influenced by peers and the media, children with disabilities may experience distinct limitations in knowledge and communication about sex education and sexual behaviour” (Cole and Cole, 1993, p192).

Social networks are fundamental in establishing the adolescent's sexual identity, helping them learn to become comfortable with their body and sexual feelings. This is critical for establishing more intense and intimate relationships into adulthood and for developing a healthy and positive adult sexual identity and achieving sexual adjustment (Cole and Cole,

1993; Gordon et al., 2004). Individuals who do not have access to these experiences and opportunities may experience difficulties establishing a sexual identity and intimate relationships in adulthood (e.g. Howland and Rintala, 2001; Shuttleworth, 2000).

3.5.2 Social Networks and Other Health Behaviours

As young people make the transition from school to employment or further education/training, they are increasingly likely to find themselves in new social situations. This is likely to involve meeting new people, such as classmates or work colleagues (Pavis, Cunningham-Burley and Amos, 1998). For instance, starting work may effect a person's social network as they come into contact with an increasing number of people, creating opportunities to engage in new and varied social activities, such as socialising in pubs/clubs and the like (Pavis et al., 1998). These changes in friendship patterns may also have implications for health behaviours. Pavis et al. reported: "It was those young people whose core friendship group smoked and/or drank regularly, whose social life revolved around pubs or clubs and whose income had risen, who were most likely to have increased tobacco or alcohol consumption" (p. 1415). There is substantial evidence to suggest that one of the main reasons young people drink is for social facilitation and to obtain peer acceptance and approval (Kuntsche et al., 2005; Pavis et al., 1998). In addition, research exploring how young people learn about alcohol and its effects has shown the main route to be through personal experience, witnessing effects on friends, family and other individuals (The Commission for Children and Young People, 2005). In many Western societies alcohol use is a normative behaviour among most adults. Therefore adolescents may experiment with alcohol as part of their transition into adulthood (Kloep et al., 2001). Learning about alcohol through trial and error can include very negative experiences (Kloep et al., 2001). Risky behaviours in general can be seen as a way young people experiment with and develop their identities. However, young people with disabilities may be disadvantaged here, as they are may not enjoy the same opportunities to socialise with their peers and participate in community life, their knowledge and experience of alcohol and other health issues may be very different. In turn this could prevent them from learning the skills required to deal with such situations should they arise. Wheatley (2005), for example, discusses how young people with disabilities may be more likely to comply with risky

requests from peers and become involved in risky behaviours, such as sexual activity, when they are not ready.

It has been argued that taking risks is an important part of the learning process, helping individuals to develop an understanding of what is safe and risky for them (Coleman et al., 2007a). In particular, parents of young people with disabilities may find it difficult to strike a balance between allowing their child autonomy and a 'normal' life, versus the need to protect them from harm (Cole and Cole, 1993). Research suggests that young people with disabilities are often slower at achieving separation from parental supervision and experience more restrictive parental rules than their non-disabled peers (Murtaugh and Zetlin, 1990). Therefore, although parents might be supportive and play a fundamental role in helping their child's adjustment to their developing sexuality, their continuing supervisory role may, in some respects, be a hindrance. A study by Markova, Stirling and Forbes (1984) illustrates the dilemma that parents of young people with intellectual disabilities face. They found that mothers of children with haemophilia restricted their child's access to metal toys or to toys with sharp edges. However, these children were less proficient and more excitable with sharp objects than the control children, making them more accident-prone and as such placing them at greater risk. Consequently, these mothers' wish to keep their children safe by restricting their access to sharp implements had the unintended consequence of preventing them from becoming more skilled with sharp objects and at greater risk of harm in the long-term (Markova et al., 1984). This suggests that it is appropriate to allow young people to engage in some health risk behaviours, thereby allowing them to learn to manage future challenges (Coleman et al., 2007a).

3.6 Parents Influence on their Child's Developing Sexuality

When the voices of young people with disabilities are listened to, a recurrent theme is the desire for greater independence. In the Scottish Human Services Trust (SHS, 2002) study, the young people with disabilities interviewed felt they had little control or choice in many aspects of their lives, including leisure activities, where to live, what to spend their money on, when to go to bed, and their college/career options. Other studies have reported young people identify 'not feeling allowed' as a barrier to leisure participation (Buttimer et al., 2005). Parents in

Buttimer et al's study worried about the safety of their child in the community, often a real concern as many of their offspring had experienced harassment. Similar findings have been reported with young people with physical disabilities. Blum et al. (1991) interviewed 162 adolescents aged between 12 and 22 with either spina bifida or cerebral palsy. Although the majority felt their parents treated them in an age-appropriate manner (i.e. allowing them to engage in social and physical activities), 24% of those individuals with spina bifida and 33% with cerebral palsy felt that their parents infantilised them. Around one quarter of participants felt their parents were overprotective, as exemplified through 'excessive assistance, recommending avoiding activities, constant vigilance, constant reminders for self-care, and being overly deferential' (p281). Participants protested against and resented this child-like treatment and overprotection, and in fact demonstrated significantly lower happiness, self-esteem, and perceived popularity. They were also self-conscious and demonstrated higher levels of anxiety than peers who did not experience overprotection. Greater supervision from parents or carers may lessen privacy, thereby reducing opportunities for spontaneous exploration where individuals may learn about themselves and their sexuality (Cole and Cole, 1993). Often in the drive to protect young people and shelter them from harm, adults avoid addressing these sensitive topics, yet this can lead to increased vulnerability if the young person lacks the knowledge, skills and understanding they need to lead confident, healthy and independent lives.

In addition to the issue of overprotection, many parents struggle to see their developing child as a sexual being (Rose, 1990), which could have major implications for the young person's sexual identity. Many parents believe that their child is not interested in the opposite sex and are often unaware that they are sexually active (Cheng and Udry, 2003). Parents may deliberately discourage developmentally appropriate behaviours such as kissing, holding hands and dating as they fear it may lead to ridicule by other children (Di Giulio, 2003) or may encourage inappropriate behaviours (Cheng and Udry, 2003). As the parent tries to protect their child from negative experiences, they may also inadvertently give out negative messages about sexuality. The transmission of attitudes and values does not have to be direct. By saying nothing about sexuality to their child, a parent is in fact saying something (i.e. that sexuality expression is not appropriate; McCabe, 1999; McCabe, Cummins, Reid, 1994). In addition, if young people perceive others to hold negative attitudes to sexuality then they will

be less likely to initiate discussions themselves. In turn, not discussing one's thoughts and feelings with others can lead to individuals having negative attitudes (McCabe, 1999).

One reason that parents may be fearful of broaching the topic of their child's sexuality is due to concern over their vulnerability to abuse (Swain and Thirlaway, 1996). Rates of sexual abuse would appear to be higher amongst both individuals with intellectual disabilities and physical disabilities, particularly in females, than with the general population. In reviewing prevalence studies of abuse in individuals with intellectual disabilities, McCarthy (1999) reports rates varying from 25% and 83%. In her own in-depth work, McCarthy (1999) found that 14 out of the 17 women with intellectual disabilities interviewed reported at least one act of abuse (although her sample may have been biased as participants were recruited from services providing information and support on sexuality and relationships). However, she also noted that prevalence rates vary widely across studies, in part due to differences in definitions of abuse, populations sampled, research methods, whether gender was taken into account (i.e. prevalence appears to be higher in females than males), and who is reporting the abuse (i.e. staff versus the individual). Possible reasons for this high prevalence might include dependency on others, inadequate knowledge, lack of awareness of appropriate and inappropriate behaviours, lack of assertiveness, and social isolation (Di Giulio, 2003; Sobsey, 1994). Cole and Cole (1993) discuss the importance of 'touch' in human development, but for many individuals with disabilities touch is experienced in a different way to those without disabilities. Touch becomes less to do with love and tenderness and becomes associated with health care, such as handling and positioning. Similarly, a young person with physical disabilities may experience many medical procedures and examinations involving public nudity and being touched by strangers, often without discussion with the individual. This has important implications for personal boundaries, appropriate and inappropriate touch and the concepts of public and private may become blurred (Cole and Cole, 1993). McCarthy (1999) discusses how definitions of abuse can vary greatly, including physical and violent sexual abuse (i.e. rape), to sexual exploitation where an individual is unable to make informed choice about the sexual act (i.e. through lack of knowledge), but may also include situations where an individual has given consent to sexual activity, but others may have abused their position of power to gain this consent (McCarthy, 1999). Therefore, it is not surprising that parents and families may feel protective of their child with disabilities. However, to emphasise, *any* parent

is generally not good at accepting and dealing with their child's developing sexuality (Craft, 1983), and parents of people with disabilities "should not be judged anymore harshly than other parents if they do not wholly welcome signs of developing sexuality in their daughters and sons" (McCarthy, 1999, p56).

3.7 Sources of Sex and Relationship Education: Parents, School and other Sources

Sexual education presents numerous dilemmas for any parent, but for the parent of a young person with intellectual or physical disabilities there may be additional challenges. Parents may be uncertain as to how much their child can understand and how having a specific disability affects their child's sexuality. Parental concerns may include their offspring's social functioning, genetic implications, parenting ability, and the physical demands of childbearing; Blum, 1997). Cheng and Udry (2003) explored how parents of children aged 12 to 18 years of age, with and without disabilities, differed in respect of delivering sex education. Parents whose child had a mild or severe intellectual disability perceived themselves to be less knowledgeable when talking to their child about sex and birth control than did parents of a non-disabled child, reporting that it was harder to explain and that their child would become more embarrassed. These views were expressed more strongly by parents whose child had a severe disability, who did not see themselves as primary sex educators and were less likely to talk to their child about sex, pregnancy, birth control and sexually transmitted diseases than parents of young people without disabilities. For example, among parents whose child had a mild intellectual disability 17-27% reported never discussing sex, pregnancy or sexually transmitted infections with their adolescent, and this increased to 45-55% if their child had a severe disability. For parents of adolescents without disabilities, this figure was 6-12%. Parents believed that their child could access information from other sources, although it was clear from Cheng and Udry's (2003) study that this was not the case. Fewer young people with disabilities reported that they had learnt about AIDS or pregnancy at school than their non-disabled peers. However, as a significantly larger proportion of the young people with disabilities in this study were non-white and came from socioeconomically disadvantaged families, caution should be taken in generalising these findings.

Blum et al. (1991) reported similar findings for young people with physical disabilities, with only 52% of young people with spina bifida and 58% with cerebral palsy having received sex education classes. Moreover, only one third of adolescents with spina bifida and 47% with cerebral palsy had discussed pubertal maturation with their parents. Amongst female participants, 53.7% with spina bifida and 56.5% with cerebral palsy had discussed menstruation with their mother, and these discussions were said to be brief, not informative, and the content could not be recalled. As this chapter has highlighted, young people with disabilities may not have the same social and learning opportunities in relation to sex and sexuality, and as such parental support is more crucial for these young people. However, not only do parents face barriers when thinking about sex and sexuality issues and their child, young people themselves may be reluctant to initiate such discussion with their parents for fear of negative reactions or that to do so might imply that they were sexually active (Morrison, 2006). Young people with disabilities themselves have made it clear that they want to know more about sexuality and relationships (The TASC Agency, 2005). If young people with disabilities lack appropriate sexual education and opportunities to explore their developing feelings and ideas, they may be forced to access other sources of information, which may be less reliable and accurate. McCabe (1999) reported that in a sample of adults with ID approximately 50% of people with disability had not experienced any form of sex education. These individuals tended to use less reliable sources for sexuality-related information, such as the media, and discussed sexual matters with family (parents or siblings) or friends less frequently than the general population. Obtaining information from such sources may lead to over-reliance on unrealistic images, and expectations of romance and intimate relationships, which may distort their knowledge of dating behaviour (Howland and Rintala, 2001). More over these sources may result in gaps in knowledge of other topics such as sexual intimacy, sexual experimentation, and homosexuality (Corker, 2001). In addition, obtaining information passively from media such as television means that young people cannot check the accuracy of the information they receive and are less likely to discuss their thoughts and feelings with others, or their experiences and needs in relation to sexual matters (McCabe, 1999).

The focus so far has been on the parents' role in their child's sex education. Many parents of young people with disabilities work hard to provide their child with a 'normal' and fulfilling

life and are positive about the possibility of their sons and daughters sexuality. However, they also report having a lack of information and support in relation to this area (Garbutt 2008). In addition, parents may encounter negative societal attitudes towards sexual expression by their child with disabilities, which makes accessing information and support even more difficult. Historically the sexual rights and needs of people with disabilities have been denied; at one extreme, individuals have been seen and treated as asexual and child-like and in need of protection and at the other, as overly interested in sex and sexually deviant (McCarthy, 1999). Although there is evidence that attitudes toward individuals engaging in sexual activity are becoming more liberal (Cuskelly and Bryde, 2004; Oliver et al., 2002; Yool, Langdon and Garner, 2003), some attitudes persist that are likely to create significant barriers to supporting young people's developing sexuality.

In conclusion, it is clear that the young people with intellectual disabilities can be confronted with many structural and attitudinal barriers to their sexual development and expression and social exclusion may reduce the available sources of formal and informal information on sex related matters. A lack of sexual knowledge or misconceptions could lead to vulnerability and distress as well as hindering the development of a healthy and positive sexual identity.

Chapter 4: Understanding Adolescent Health Behaviour

4.1 Adolescent Health Psychology

Prior to the twentieth century, health and illness were predominantly viewed from a 'biomedical model', where the causation of illness was considered to be the result of biological changes (i.e. viruses, chemical imbalances, genetics). From such a perspective, the individual was perceived to play a very passive role in their health and illness status, the mind and body were seen very much as two separate entities (Ogden, 2007). However during the twentieth century, this mind-body dualism began to be questioned, and the influence of psychological factors on physical health was increasingly acknowledged. This change was reflected by a number of emerging approaches such as psychosomatic medicine, behavioural health and health psychology, which are overlapping areas of study. Psychosomatic health explores how illness is caused and/or maintained by psychological dynamics. It includes the study of psychological and emotional factors in conditions that appear to have no organic basis, as well as organic conditions. This approach, initially founded on the psychoanalytic theories of Freud and Alexander, proposed that personality traits and unconscious conflicts are associated with physical illness (Alexander, French et al., 1948; Breuer and Freud, 1955). An often cited example is the condition of 'hysteria' where psychological factors were purported to be the cause of physical illness. Behavioural health conversely, draws on theories of learning, research on animal psychology, human psychophysiology, and social and clinical psychology (Schwartz and Weiss, 1977). It stresses individual responsibility, focusing on behavioural approaches for the treatment and prevention of disease and education to allow the adoption of a more healthy behaviour. For example, tackling smoking and obesity as well as increasing compliance with medication and pain management.

Health psychology adopts an interdisciplinary approach to health and illness, and is the most recent field of psychological research to emerge as a reaction to this mind-body dualism. The approach reflects the principles of the 'biopsychosocial' model of health and illness, introduced by George Engel in the 1970s. The general model that posits that health and illness

is the product of a reciprocal and dynamic interaction between biological, psychological and social factors. In this way, Health psychology acknowledges the role of the individual in the onset, prevention and treatment of illness. Researchers therefore turned their focus to social cognitive variables that determine health and illness behaviours, such as knowledge, beliefs, attitudes, emotions and behaviour. It is anticipated that by identifying psychological factors most proximal to behaviour and amenable to change, one can influence the onset and progression of illness (Armitage and Conner, 2000).

Over the last few decades, mainstream health psychologists have attempted to delineate and predict health- and illness-related behaviour, through the development and testing of models and theories. A large number of theoretical models have attempted to link these factors, being roughly divided into cognition models and social cognition models, both of which see the individual as a rational information processor. In cognition models, such as the Health Belief Model (HBM; Becker, 1974), emphasis is given to the role of individual cognitions in determining behaviour. The HBM proposes that the likelihood of a behaviour occurring is determined by a number of core beliefs. These include perceived susceptibility ('my chances of getting heart disease are high') perceived severity ('heart disease is a serious illness'), perceived costs ('changing my eating habits will be expensive') and perceived benefits ('changing my diet will help me lose weight'; Ogden, 2007). Later revisions of this model include constructs such as 'health motivations' ('I am concerned that my diet is damaging my health') and 'perceived control' ('I can change my diet if I want to').

Social cognition models, such as the Theory of Reasoned Behaviour and the Theory of Planned Behaviour, also attempt to measure the impact of social and environmental factors influencing individuals. The Theory of Planned Behaviour (TPB) is one of the most influential and widely applied social cognition models in health psychology. The TPB was proposed by Ajzen (1985, 1988, 1991) and was an extension of the Theory of Reasoned Action (TRA: Fishbein and Ajzen, 1975). The TRA was originally developed in response to the lack of a consistent relationship between attitudes and behaviour. According to the Theory of Reasoned Action, the primary and immediate determinant of behaviour is the person's intention to perform the behaviour (Ajzen, 1991). In turn, behavioural intention is determined by attitude towards the behaviour, including beliefs about the perceived likelihood that performing the

behaviour will lead to valued outcomes. Subjective norms are perceived social pressures to behave in a particular fashion and the person's motivation to comply with these social influences. A combination of these factors is thought to lead to the development of an intention to perform or not perform behaviour. The construct subjective norm is said to account for social influences on behaviour, whereas attitudes are personal influences.

The Theory of Planned Behaviour (TPB) was developed to account for non-volitional behaviours through the addition of the variable 'perceived behavioural control' (PBC). This added construct refers to the individual's perception of their ability to perform a given behaviour and is closely related to Bandura's construct of self-efficacy (Bandura, 1998; Ajzen, 1998). The TPB has been applied to various behaviours, accounting for approximately 50% of the variance in intentions (Ajzen, 1991; Armitage and Connor, 2001; Sheeran and Taylor, 1997). Although this model has been successful in predicting many behaviours, particularly health promoting behaviours (for a meta-analytic review see Armitage and Connor, 2001), there is still a substantial proportion of the variance in behaviour that remains unaccounted for. In addition, the weakest predictors of intentions are subjective norms, with personal factors being better associated with intentions (Armitage and Connor, 2001; Ajzen, 1991). One may predict that social factors would have a particular importance for adolescents. However, social influence in these health behaviour models usually consists of finding out what the target individual thinks other's attitudes will be towards their actions. This does not necessarily capture the dynamic and sometimes contradictory social influences people are exposed to, especially in adolescence. For example, some behaviour may be a way of establishing an independent identity by rebelling against parental views. These social influences have to be understood in relation to individual developmental stage and the broader social context.

Another criticism is that mainstream health psychology models view human agency as rational. In other words, an individual will rationally weigh up the costs and benefits of a behaviour to determine whether or not it should be enacted, with the focus mainly on individual cognitions. This has led to a situation where much of the research conducted in this area has been directed at variables operating at the individual level. For example, it is assumed that by gaining understanding of the consequences of unhealthy behaviour people will make healthier choices. such as quitting smoking, reducing alcohol consumption and adopting

healthy eating practices (Crossley, 2000). Whereas some see the dangers of an overemphasis on personal responsibility and believe it may lead to a culture of personal blame (Marks, 1996), others have argued that such an approach allows an individual to feel empowered and in control of their life. However, by focusing on factors at an individual level, other important determinants such as social and community influences, living and working conditions and broader socio-economic, cultural and environmental conditions are neglected (Marks, 1996). Despite some health models trying to incorporate measures of the social context, such as the TPB, this is usually done through individual report, rather than measuring environmental influences on behaviour (Marks, 1996).

To obtain a better understanding of people's decisions and actions in relation to health there is a need to access their thoughts and perspectives, not what researchers believe is thought and felt. Critical health psychology emerged reactively to critiques of mainstream health psychology. Critical psychologists argue that there is a need for an alternative approach to understanding human experience in relation to health and illness, one emphasising the importance of cultural and moral milieu (Crossley, 2000). It is proposed that through our everyday activities, through discussing, interacting, and negotiating with others, we create a sense of identity (Crossley, 2000; Lupton, 1994). It is this continual process of constructing ourselves that gives us direction, meaning, value and purpose in life. Moreover, this does not occur separately in each individual's mind, but occurs in the society and culture in which we live. Therefore our interpretations of health and illness only make sense in relation to people's social and cultural contexts (Crossley, 2000). As with many advocates of Critical Health Psychology, Marks (1996) argues the need for experiences of health and illness to be understood from a structural perspective that moves beyond consideration of social and cognitive factors at an individual level.

Social cognition models have also been criticised for relying upon structured questionnaires to assess individual cognitions, such as beliefs and attitudes. However, the process of completing a questionnaire itself may influence or change participants' beliefs or attitudes (Ogden, 2003). Ogden cited a study by Cecil et al. (1999) that assessed the utility of the HBM in predicting intention to use the female condom. Participants were asked to complete a questionnaire assessing their attitudes toward the female condom, including items such as 'the female

condom decreases sexual pleasure for a man'. However, as 93% of the study sample had never used a female condom before, it is likely that pre-existing cognitions were not being assessed, but that individuals were being influenced to think in new ways (Ogden, 2003). This in turn may influence actual behaviour (Ogden, 2003). Critical psychologists argue that complex subjective human experience cannot be easily quantified and reduced to these simple constructs. To achieve a deeper understanding of health and illness behaviour, and how this relates to contemporary social life, necessitates a more qualitative and in-depth approach (Crossley, 2000). Young people and health-risking behaviour may illustrate this point as it is now well established that young people choose to engage in risky behaviours even when they are fully aware of the health risks involved. From a health perspective, this behaviour appears nonsensical. However, accessing the narratives of young people themselves frequently reveals that just because behaviour may have an impact on health, it does not necessarily mean that health is the motivating factor. For example, sexual intercourse is about many things, including attraction, intimacy, risk, romance and pleasure. Health may not be a major consideration for sexually active young people (Thorogood, 1992), yet the assumed priority of health concerns often form basis for constructing health interventions. Even when measures of social context have been incorporated in models of adolescent health behaviour, they are hypothesised to be additional independent factors that might predict behaviour, or as offering 'essential background information' (Ioannou, 2003, p359). Consideration is not given to the complex relationship between the individual and their wider social context.

4.2 Understanding Adolescent Health Behaviour

The preceding section has highlighted the importance of considering the broader context of young people's lives when examining their health related behaviours. Such approaches are important for developing effective and relevant health education and promotion strategies. The importance of accessing young people's own perspectives when attempting to understand their behaviour was also emphasised. This means viewing health-related behaviours as more than 'problems' that need to be solved and starting to explore what behaviour means to young people themselves.

4.2.1 Health Related Behaviours, Consumerism and Identity

Debates within sociological theory have focused on the relative importance of, and interactions between, individual agency and social structures in determining human thought and behaviour. At one end of the spectrum, theorists have posited that social structures in society, such as gender and class, constrain individual behaviour. From this perspective the perceived agency of individuals can be explained almost entirely by society's structure (Durkheim, 1893). Theorists at the other end of the spectrum have focused on individual human actors and the subjective meanings they attach to their actions (Weber, 1904-05/1958), emphasising reflexivity and agency (Côte and Levine, 2002). It is argued that as humans we constantly reflect on our own behaviour and environment, evaluating and adjusting it according to our own set of commitments and values (reflexivity; Crossley, 2000). Proponents of this view see individuals acting independently of social structures and making their own free choices on the basis of this reflexivity (Côte and Levine, 2002). Individuals are able to construct and reconstruct their worlds, fashioning their identities from a range of experiences and opportunities (Pavis et al., 1998). It has been argued that changes in contemporary society, such as less secure careers, increased risk of unemployment, disintegration of communities, and less stable family structures (Roberts, 1997), have weakened traditional social structures. Consequently, traditional social markers such as age, sex, occupation, and class that once gave people their identity and role in life hold less influence over behaviour (Baudrillard, 1988). In turn, such social change is thought to have left individuals less certain about their identities (Giddens, 1991). Denscombe (2001) argues that modern societies allow greater variety of social contacts and occupation of social roles. Yet many of these relationships and roles are transitory and shallow and play a limited part in defining the self. In turn, it has been argued that this leads to a more 'fragmented self' or identity, and consequently individuals look for new ways to define themselves:

The point is that the consistent and coherent self becomes more problematic as it shifts in status from something ascribed by status to something to be achieved and continuously reiterated. Personal identity and a sense of one's 'self' is something which needs to be consciously constructed and maintained, directed and shaped, in relation to its social environment. (Denscombe, 2001, p161).

It has been argued this may be more salient for adolescence (Denscombe, 2001; Miles, 1998; Pavis et al., 1998). As Miles et al. note, young people are 'more adept at, and more willing than adults, to experiment with their identities, no matter what boundaries (whether they be class, gender or race) of identity, may appear to constrain them' (Miles, Cliff and Burr, 1998; p83). Therefore, although structural factors may still be important for building meaningful identities, greater significance is now attached to the central role individuals play in shaping and constructing their identities (Denscombe, 2001; Furlong and Cartmel, 1997; Pavis et al., 1998). One way that young people 'try on' new identities is through lifestyle choices and consumption.

However, before discussing lifestyle choices and consumption further, it is important to consider some of the challenges facing young people during transition to adulthood and the potential implications these have for health and well-being. Today's youth in the UK face a very different social situation to that of even a decade ago, and it has been argued by some authors that this has implications for leisure and health-behaviours (Furlong and Cartmel, 1997). It has been acknowledged that the nature of transitions to adulthood is changing, which in part results from rapid societal changes. Whereas once transitions were relatively straightforward and predictable, in contemporary society they have become more complex and individualised (Mackinnon, 2007). Greater Protraction refers to the idea that the 'youth' period is becoming lengthier while, puberty and sexual relations occur earlier. Marriage, parenthood, entry into the workforce and financial independence are delayed with increasing numbers of young people prolonging education (Furlong and Cartmel, 1997). This partly results from the changing nature of the labour market, where gaining qualifications has become more important in securing employment (Coleman et al., 2007a; Furlong, 2002). This creates a situation where individuals remain dependent upon their families, for example for financial support, while striving for adult independence (Coleman et al., 2007a). It has been argued that this uncertainty at transition has implications for young people's psychological and physical well-being (Coleman et al., 2007a; Furlong, 2002).

As the period of transition to adulthood has lengthened, it is proposed that young people may have greater opportunity for risk-taking behaviour (Furlong and Cartmel, 1997). This could be a result of youths spending larger amounts of time in the company of their peers, who play an

important part in shaping their attitudes and behaviour in unstructured and adult-free contexts (MacKinnon, 2007). 'Hanging out with friends' has been associated with increased substance use (smoking, drinking and drug), whereas taking part in organised activities, such as sports and hobbies is negatively associated with substance use (Sweeting and West, 2003). Sweeting and West examined gender differences in leisure activities of two cohorts of 15 year olds between 1987 and 1999 in Scotland. Female leisure activities became more 'public' or 'visible' over this period, for example hanging about on the street and seeing friends; activities that were once dominated by males. At the same time gender differences in risk taking behaviour were reduced over time, with female levels of drinking and illicit drug use matching that of males. Rates of smoking were higher for females than males. The authors reported that changes in leisure activities over time accounted, in part, for the changing gender patterns in substance use (Sweeting and West, 2003). This may be linked to changing gender constraints on young women's lifestyles and leisure participation and the weakening of gender differences (Furlong and Cartmel, 2007; Sweeting and West, 2003).

Despite significant societal change, social norms concerning characteristics such as class and gender remain important in shaping identities, even if they do not 'supply as well defined and powerful collective identities as in the past' (Roberts, 1997, p11). For example, Pavis, Cunningham-Burley and Amos (1998) described how adolescents making the transition from school to employment or further education/training found themselves in new social situations, met new people and enjoyed greater autonomy. However, these young people's leisure and lifestyle choices were still constrained by structural limitations, such as their educational achievement, the resources and opportunities available to them, work commitments, and levels of income.

4.2.2 Consumerism and Young People's Identities

Consumerism refers to "a doctrine advocating a continual increase in the consumption of goods as a basis for a sound economy" (Oxford Dictionary). Consumer culture emphasises the social and cultural aspects of this process (Ioannou, 2003). In a given culture, commodities and behaviours become richly associated with symbolic meaning. What, when and how people consume can play an important role in defining people's own experiences and concepts of

themselves and their world (Featherstone, 1991). For example, individuals actively define themselves by the clothes they wear and the brands of foods and drink they consume (Lupton, 1994). As an individual chooses to engage in various behaviours, they become linked with a 'certain way of life, a certain personality, a certain social class' (Lupton, 1994. p112). Engaging in these behaviours thus not only signifies to oneself a desired image, but communicates this to others as well (Lupton, 1994). Take the example of physical activity. From public health and medical discourses the motivation to engage in exercise is that it will benefit one's overall health and life span. However, in Western society, physical activity is associated with a range of characteristics, experiences and meanings. It can be a way of signifying youth and attractiveness, discipline and self-control, or be a rejection of other norms or stereotypes, such as the impact of aging (Lupton, 1996). Self-improvement may be one way of regaining a sense of control over one's life in an uncertain world by regulating how much and how hard we exercise and how much we eat (Crossley, 2000). As health-promoting behaviours become laden with cultural symbols and meanings, so do health-risking behaviours. For example, by drinking alcohol to excess, smoking or engaging in unsafe sex practices, people may be resisting 'dominant culture values', asserting their own independence, autonomy, and identity (Crossley, 2000).

There are a number of reasons why consumerism may play a more central role in relation to young people's identities. Firstly, social changes faced by modern youth discussed above, such as weakening social structures and increased risk of unemployment, have led to greater risks and uncertainties in their transitory phase. Consumption is one way that young people can negotiate social status and thus develop and articulate their identities (Rugkåsa, Kennedy, Barton, et al., 2001). In addition, protraction of this childhood to adulthood transition phase increased leisure time and access to resources, allowing youth to "prioritise their free time and at a point in their lives when they have fewer responsibilities than they are ever likely to have in their futures" (Miles et al., 1998. p83). Consequently, how young people spend their leisure time is central to understanding how they come to shape their own identities. Finally, the media play a large role in consumer culture, targeting young people through advertising, TV and film, and the Internet. In contemporary society, young people are media literate and as a result are very aware of the symbolic value in commodities (Amos, Gray et al., 1997).

It is fairly well established in the literature that children and young people are aware that people engage in health related behaviours, such as smoking or drinking alcohol, to convey certain images to others. Presenting the right image through these behaviours is one mechanism through which young people negotiate status in their social world (Rugkasa et al., 2001). For example, Ioannou (2003) explored how young people aged between 15 and 17 years talk about smoking, eating, drinking alcohol and exercise in the context of their everyday lives. For these young people, health behaviours took on aesthetic values, as exemplified by the use of words such as 'attractive' and 'stylish', and allowed them to achieve a more stylised life. Exercise was associated with 'achieving 'a good appearance', consuming alcohol made one appear more 'attractive' and smoking was associated with looking 'cool' or 'stylish'. Justifications given for engaging in such behaviours did not refer to health, but to projecting certain images to their peers. Participants expected themselves and others to be 'trendy', 'different', 'fashionable', 'relaxed', 'risky', and 'older' and they associated these characteristics with health behaviours. Similar findings have been reported elsewhere, for example with children as young as 10 and 11 years of age (Rugkasa et al., 2001) and adolescents aged 15 to 16 years (Denscombe, 2001) discussing how smoking can convey certain images such as looking "grown up", "big", "cool" or "hard". Denscombe (2001) also reported gender differences in the image value associated with smoking, involving a more specific role for females in asserting their equality with their male peers. Lloyd and Lucas (1996) reported that smokers rated themselves more negatively on general positive-negative dimensions such as happy, healthy, or unhealthy and unpopular, than non-smokers. However, smokers also rated themselves as more fun loving (e.g. liked partying, attracted to the opposite sex, cool) and less conforming (e.g. don't care about the environment, rule breakers) than non-smokers. Smoking was associated with an increased desire to become more fun-loving and less conforming; that is, there was a larger discrepancy between actual and ideal self ratings reported by smokers than non-smokers.

Amos et al. (1997) explored differences in the self-image and ideal image of smokers and non-smokers aged 12 – 13 years, 15 – 16 years and 18 – 19 years of age. Focus groups were used to elicit attributes used by young people to describe smoking and non-smoking images. These were then incorporated into a self-completion questionnaire and participants asked to rate their self and ideal images on each of these attributes. Overall the authors reported that smokers,

particularly males, were more likely to embrace the self- and ideal-images of 'druggy/takes drugs' 'wild' 'tough' and 'tarty' than non-smokers. This finding was particularly strong for 12 – 13 year olds. The authors suggested that for this age group, smoking is strongly discouraged and is frequently associated with intimidating behaviour and deviance. However, for some individuals, this was the very reason that they took up smoking, to appear rebellious and independent. Smokers in the study saw themselves as less healthy than non-smokers and aspired to be more 'healthy'; however the authors suggested that although these individuals valued their health, the immediate impact of being a smoker on the self-image was more important to them than their health. It has been suggested that for young people, long-term health consequences of their actions has little influence on their behaviour because they tend to think and act in a more immediate time frame (Mackinnon, 2007). On the other hand, female smokers aged 12–13 years were more likely to rate their self-image as sexy/seductive and their ideal image as sexy, slim and attractive than non-smokers, an attempt to adopt adult behaviour (Amos et al., 1997). Female smokers aged 15–16 years were more likely to describe their self-image and ideal image as trendy/fashionable, illustrating the link between fashion, style and smoking behaviour. The ratings of female smokers aged 18–19 years were similar to those of male smokers, rating their self-image as wild, cool, tough, and arrogant and their ideal image as wild and cool. The authors suggested these images reflect those portrayed in the media and as were more central to the self-images of older female smokers. However, self and ideal images were assessed through a questionnaire, requiring participants to rate how much each attribute described them and how much they would like the attribute, using constructs like healthy, druggy, trendy/fashionable, and wild. Although these traits were developed through focus groups with young people, it is not clear how accurately a single word can capture the complex nature of such images. In addition, these words are likely to conjure up different images and meanings for different people.

Social processes and expectations also shape young people's sexual behaviour. Marston and King (2006) conducted a global systematic review of factors shaping young people's sexual behaviour (involving 268 qualitative studies published between 1990 and 2004, and covering all regions of the world). They reported that individuals often reported engaging in sex as a way to please their partner and to strengthen relationship. In addition, the participants described clear images associated with sexual behaviour, although these differed for males and

females. For example, carrying a condom could imply sexual promiscuity in women, whilst men rated this and the image of males being sexually active and experienced, seeking pleasure, having many partners positively, with sexual intercourse often being viewed as a transition into adulthood. Women however were expected to be chaste, less experienced and seeking a stable monogamous relationship. If they desired sex then women were seen as promiscuous or 'cheap' and 'loose'.

Young people may associate multiple meanings with health behaviours and these meanings are not fixed, but can be influenced by the social context. For example, one person may associate smoking with looking 'popular' and 'mature', whereas another young person may think it portrays someone as 'weak' or easily influenced. In the context peer socialisation, smoking may be experienced as 'trendy' and 'cool', but when in the company of adults a young person may be aware that smoking is perceived negatively (Ioannou, 2003). Consequently, there may be no one definitive answer to what motivates young people to engage in health risking behaviours, although more often than not it may have little to do with health.

4.2.3 Control and Independence

A common theme emergent from the qualitative studies is that many young people's health behaviours are associated with a desire for autonomy. Engaging in health behaviours is one way that young people can demonstrate their autonomy and some control over their lives, of importance as they are at the transition between youth and adulthood. In a qualitative study conducted by Watt and Sheilam (1997), young people were found to associate cheap and instant fast foods with control and independence. In addition, the authors reported that consuming these foods brought them into conflict with their parents, which gave such food an extra appeal. Similar findings have been reported in relation to smoking behaviour. In the study by Denscombe (2001) young people reported (aged 15 to 16 years) choosing to take up smoking as it made them feel in control of their lives. In addition, not only did smoking give the appearance of being in control to others, it also symbolised to the young person control of their life and their destiny.

4.2.4 Negotiation with the Adult World

The individual who reaches adolescence is no longer considered a child, nor yet considered an adult either. In our society, we do not have rituals to mark the transition into adulthood, and as such there is a lengthy period when a young person is left uncertain about their status in society (Rugkasa et al., 2001). One way in which adolescents can negotiate their passage into adulthood is through experimenting with ‘adult’ behaviours, such as smoking and drinking. For example, Rugkasa et al. (2001) demonstrated that 10 and 11-year-old children view smoking as exclusively an adult activity and that their peers would smoke to convey images such as ‘looking grown up’. In a cross national study, Kloeppel et al. (2001) reported that young people living in Scotland viewed themselves as living in a drinking society and therefore to drink alcohol was seen as an inevitable part of making the transition to adulthood. Similarly, some young people view bad experiences in relation to alcohol consumption as necessary rites of passage into the adult drinking world (Potter, 2002).

With regards to sexual behaviour, Shucksmith and Spratt (2002) note that the “boundary between child and adult seems more confused than ever” (p13). As young people in contemporary society are very media literate, it is not surprising that even very young children are exposed to a highly sexualised world. For example, sexual images are closely linked to clothing and brands, music (Shucksmith and Spratt, 2002), magazines, films and so forth.

4.2.5 Socialising with Friends and ‘Just Having Fun’

Research that has explored young people’s reasons for engaging in risky health behaviours has highlighted the significant role they can play in socialising with peers. As discussed in chapter 3, during adolescence individuals invest greater time and effort into developing more intimate and romantic relationships. In doing so, they may find themselves in social situations where health risking behaviours are prominent, for example drinking in pubs or at parties. There is evidence to suggest that young people who drink are more sociable, have better peer relations, lower levels of loneliness and more intimate relationships (Engels and van den Eijnden, 2007). Pavis et al. (1998) reported that for young people in their study, the most frequently cited reasons for drinking alcohol and smoking were social facilitation and peer influence. With

regards to alcohol consumption, focus groups with young people found the reasons given for drinking alcohol were no different from those given by adults, indicating excitement and fun, to ease shyness and to aid relaxation (Kloep et al., 2001).

The motivation for taking part in exercise is often linked to friendships and social context. For example, the social nature of sporting activities is often regarded as being more important than the sport itself (Harris, 1995). Wright et al. (2003) demonstrated how young people gave lower priority to exercise than other aspects of their life, such as work or study, with exercise only been given priority if it tied in with socialising with friends, boyfriends / girlfriends, or family. However, young people in the study were aware of the benefits of physical activity to health, with associated feelings of guilt for not doing more. In a report conducted by Barnardo's, 174 children and young people aged 4 to 15 years took part in group interviews eliciting their views about social and environmental factors that influenced their food preferences in school (Ludvigsen and Sharma, 2004). It was found that friends often influenced children and young people's decision to eat school meals or packed lunches. For instance, they were motivated by the desire to sit with friends and socialise at lunchtimes. It was clear that friendships and socialising were valued above what food was actually eaten. The report also found that there were many unwritten rules about what the children could include in their packed lunches. For example, to bring in food that deviated too much from the traditional sandwich on white bread, like fish, rice pudding, salad or too many vegetables could lead to ridicule. Children and young people also knew about different brands of food, and buying cheaper brands communicated to others that their family had less disposable income and this could be stigmatising.

4.2.6 The Importance of Avoiding Negative Evaluations

There is evidence to suggest that there are individual differences in how concerned people are about others' perceptions of them. For example, Martin and Leary (2001) reported that students who were more attuned to others' perceptions of them (high public self-consciousness) or worried more about negative evaluations from others, were more likely to report engaging in risky behaviours in order to make a certain impression, such as appearing laid back, fun, a risk-taker or mature. Corcoran and Segrist (1993) reported that fear of negative evaluation was

a significant predictor of choosing an alcoholic beverage (vs. a non-alcoholic one), but only when the participant believes that fellow students will be made aware of his or her choice. Research exploring condom use has identified the importance of perceived evaluations from others:

“Twice in the last three months, I had sex without using a condom. I met this guy here and thought that I liked him a lot. He knew that I was on the pill so he told me it was okay. When I said I didn’t want to get any diseases, he just said, “don’t worry”. I didn’t want to come across in a way to make him not like me so I gave in”.

(Martin and Leary, 2001, p.68).

However, this research has focused on the experiences of university students and as such findings are not generalisable to younger adolescents or those living in different social circumstances.

Johnson and Johnson (1996) explored the perceived social consequences for accepting or refusing an alcoholic drink by children aged 6-7, 9-10 and 12-13 years. Using a vignette procedure developed by Gaines et al. (1988) to explore children’s understanding of adults’ drinking motives, participants were presented with two vignettes in which an adolescent character was offered a drink (beer) by friends. Participants were then told either that the individual accepted and consumed the drink or that they declined the drink. Following this, participants’ beliefs about why participants chose to drink or refuse the beer, as well as beliefs about parents’ and friends’ reactions were explored. There was unanimous agreement that parents would react negatively. Seventy-five percent of children discussed social motives, such as peer pressure or ‘everyone else was doing it’, when explaining the character’s behaviour, although these were discussed more frequently by older participants (45% of 6-7 year olds versus 90% of 9-10 year olds and 12 -13 year olds). Thirty-seven percent of the youngest group (6-7 year olds) believed their friends would approve of drinking, and this increased to 89% of 9-10 year olds and 80% of 12 -13 year olds. All three age groups expected friends to react negatively if they refused the drink (90% of 6-7 year olds and 9-10 year olds and 100% of 12 -13 year olds), eliciting labels such as ‘chicken’, ‘wimp’ or ‘baby’. Therefore, even children and young adolescents believed that to refuse a drink could be socially difficult.

Although this method provided insight into children and young people's views about accepting or refusing alcohol, there was one drawback. The research examined the children's views about the expected outcomes of someone else's behaviour. It is therefore difficult to know whether these individuals would have given the same responses if they were asked to imagine themselves in the same situation. They may have been well aware of what is typically socially desirable for young people to do but have a different perspective for themselves. Again this takes us back to what was highlighted at the beginning of this review; the importance of exploring behaviour from the individual's own perspective.

4.2.7 Health Related Behaviour and People with Intellectual Disabilities

The literature review on young people without disabilities revealed that young people often choose to engage in risky behaviours despite a sound knowledge of the health risks involved. This has encouraged researchers to move away from a framework that emphasises knowledge as the key to preventing risky behaviour and to focusing more on the social and cultural contexts that behaviour occurs in. However, very little is known about the motives for people with disabilities to engage in health risking behaviours. This may stem from the commonly held myth that people with intellectual disabilities have no interest in alcohol, smoking, drugs, or sex (Kalyva, 2007). However, it is clear from chapter 2 that many young people with disabilities do consume alcohol, smoke, have unhealthy eating habits, do not engage in adequate amounts of exercise and are sexually active, albeit it at lower levels than their non-disabled peers. They are therefore engaging in behaviours that have consequences for their health. Research in this area is sparse. It has tended to focus on issues such as prevalence (Emerson and Turnball, 2005; Taggart et al., 2006), risk factors for substance misuse (Robertson et al., 2000; Taggart et al., 2006), the impact of substance abuse on lives of people with ID (Clarke and Wilson, 1999; Taggart et al., 2006) and interventions (Annand and Rus, 1998; Mendel and Hopkins, 2002). There has been little exploration into their motivations for using substances, such as alcohol. The focus of research in this area has tended to be on substance misuse, as opposed to its use in everyday life as it has been for non-disabled populations (e.g. Annand and Rus, 1998; Burgard et al., 2000; Campbell et al., 1994; Christian

and Poling, 1997; Clarke and Wilson, 1999; Degenhardt, 2000; Mendel and Hopkins, 2002; Taggart et al., 2006).

There have been a handful of studies that have begun to shed light upon why people with intellectual disabilities engage in (or refrain from) health-risking behaviours. Such studies have reported similar themes as found with non-disabled populations. For example, Whitaker and Hughes (2003) reported that knowledge about smoking did not differentiate between individuals with intellectual disabilities who were smokers or non-smokers, suggesting that a lack of knowledge was unlikely to be the reason why they started smoking or failed to stop. However, the authors suggested that social influence might be important in smoking behaviour, for example living with a smoker, with individuals frequently citing family and friends as reasons why they had initiated smoking. The authors suggested that presenting a certain image, for example “to look cool” was also important. Hymowitz et al. (1997) proposed that people with intellectual disabilities who smoke are imitating the behaviour of their typically developing peers. Smoking may help to enhance self-esteem, confidence and image, and therefore acceptance. It was suggested that smoking therefore serves as a symbol of maturity and competence in people with intellectual disabilities (Hymowitz et al., 1997). Rather than imitating their non-disabled peers, it may simply be that they have the same motivations.

Huang (1981) reported differences in the reasons cited by young people with and without disabilities for drinking alcohol. Young people with intellectual disabilities were more likely to state that they drank because “they have reached the age to drink” (24% compared to 4%), “their friends drink” (31% compared to 20%), “to avoid being laughed at” (14% compared to 6%) and “to be with the crowd” (22% compared to 15%). This is an old study and the methods used were not well reported. It is unclear what young people were asked and whether differences between groups were a result of comprehension difficulties. However, it does draw attention to the notion that health behaviours are influenced by social factors to at least the same degree for young people with intellectual disabilities as their non-disabled peers, if not more.

More recently, Taggart, McLaughlin, Quinn and McFarlane (2007) conducted a series of semi-structured and one-to-one interviews with 10 people with ID who misused alcohol or drugs. Individuals in the study used alcohol to 'self-medicate against life's negative experiences', such as bereavement, mental health problems (i.e. depression), self-harm, domestic violence, physical and sexual abuse. Another prominent theme was experience of loneliness and isolation. Many of the participants discussed how they had few or no friends and lived by themselves, with a few individuals stating they drank in bars alone in an attempt to meet new people. Some reported that they drank with other people, either in their home, in pubs or on the streets, but that these other people were exploiting them for material or sexual gain. The authors discussed how alcohol was used by these participants as a means of fitting in and being accepted by their non-disabled peers and to avoid loneliness.

In a study carried out in Greece, Kalyva (2007) explored the prevalence and influences on smoking among young people with attention deficit hyperactivity disorder (ADHD), mild intellectual disability and no disability. Over 300 young people aged 12 to 16 years participated in the study, 89 of whom had a mild intellectual disability. Participants completed a self-report questionnaire eliciting information on smoking behaviour, perceived attitudes of friends and parents and smoking knowledge. Young people with ADHD smoked more than those with a mild intellectual disability, who in turn smoked more than their non-disabled peers. The authors did not find that smoking behaviour was a result of copying their parents smoking. However, young people with ADHD were less knowledgeable about the effects of smoking and reported that more of their friends smoked than did young people with intellectual disabilities and their typically developing peers. Almost all the participants believed that their parents and friends would have a negative attitude toward smoking and would actively discourage them from smoking, yet the participants were still choosing to smoke. Kalyva (2007) suggested that the social benefits associated with becoming a member of a peer group may be more important determinants of smoking for these adolescents than were the attitudes of their family and friends. Despite highlighting the potential importance of social motives in explaining health behaviours of young people with disabilities, one has to be careful in making such assumptions as young people were not asked directly why they chose to smoke. In discussing alcohol and people with intellectual disabilities, Simpson (1998) stated that:

“The literature is also prone to the acceptance and propagation of fairly crude and unsubstantiated stereotypes and assumptions, for instance about the reasons for drinking (...) Whilst there may well be some truth in some of these assertions, they appear in the literature only as anecdotes tacked on to the end of already inconclusive studies.” (Simpson, 1998, p548).

4.3 Conclusion

It is well established that many young people choose to engage in health-risking behaviours despite adequate or even high levels of knowledge regarding of the risks involved. As this chapter has highlighted, theories guiding health interventions for young people have been essentially cognitive and individualistic, failing to take into account the fact that behaviours are acted out in the social sphere and are shaped through our interactions with others. Health educators and health professionals frequently adopt a medical discourse, making the assumption that health forms the motivation or deterrence for harmful behaviour. Moreover, the different worldviews held by medically orientated academics and by adolescents themselves may, in part, explain the lack of successful interventions for health-risking behaviours (Lloyd et al., 1998). Finally it is important to note that adolescents are not a homogenous group. Human experience is rich and complex; beliefs and behaviours are influenced by a complicated interaction of factors, such as age, gender, ethnicity, and disability. Hence it is not always possible or advisable to generalise across populations. Finally, as touched on previous chapters, young people from deprived or minority backgrounds may not have same choice or freedom in their health and lifestyle choices than their peers (Furlong and Cartmel, 1997).

Chapter 5: Phase I Methodology

5.1 Introduction

The literature review revealed the need for further investigation into health behaviours in young people with both intellectual and physical disabilities. The steady accumulation of research around young people from the general population (as can be seen from chapters 1, 2 and 5) has contributed to the emergence of a more comprehensive picture of health-related knowledge and behaviours. This in turn can be used to move us forward in the design of effective health education strategies. Unfortunately, there is a dearth of research focusing on young people with disabilities.

Health related research involving young people with disabilities has predominately focused on prevalence rates of health risking behaviours, isolated attempts at exploring health knowledge and barriers to health information, with only a handful of qualitative studies exploring health from the perspective of the individual themselves. A few studies have begun to explore the relationship between social exclusion and poor health knowledge in people with disabilities, in particular with regard to sexual health. However, none have specifically explored the impact that social exclusion has on health knowledge and behaviours, using controlled comparison groups. A more comprehensive and detailed understanding of the impact of social exclusion on health knowledge is essential if we are to determine the most effective means of getting relevant information across to these young people. In turn this should help to promote positive and healthy sexual identities, thereby reducing the risk of sexual exploitation.

5.1.1 Teasing out the Role of Social Exclusion in Shaping Health Knowledge and Behaviour

Chapter 2 presented evidence indicating that young people with intellectual and physical disabilities have lower levels of knowledge in relation to many areas of health. Chapter 3 illustrated how these individuals are more likely to experience social exclusion. However, as mentioned above, with the majority of studies conducted in this area there has been a major

limitation; they have not employed controlled group designs. This limits the conclusions that can be drawn about how factors specific to having an intellectual disability impact upon the development of health knowledge. Thus, by comparing and contrasting young people with disabilities' health knowledge with their non-disabled peers, we learn about how understandings and misunderstandings develop, how misconceptions may persist, and how we may be better positioned to break down these misconceptions.

In addition, the few studies that have compared health knowledge in individuals with intellectual disabilities to their non-disabled peers have, perhaps unsurprisingly, have found these individuals to have lower levels of health knowledge (Duh, 2000; McCabe, 1999; McCusker et al., 1993; Szollos and McCabe, 1995). Whilst highlighting interesting trends, such research has tended to focus on explanations relating to people's cognitive deficits in explaining these differences, and has failed to take into account the impact of social and environmental factors (Zigler and Bennett-Gates, 1999). An underlying and unanswered question pertains to the cause of the consistent group differences reported in these studies. Lower levels of knowledge may not be associated with having a cognitive impairment alone, but could also be linked with other contextual factors.

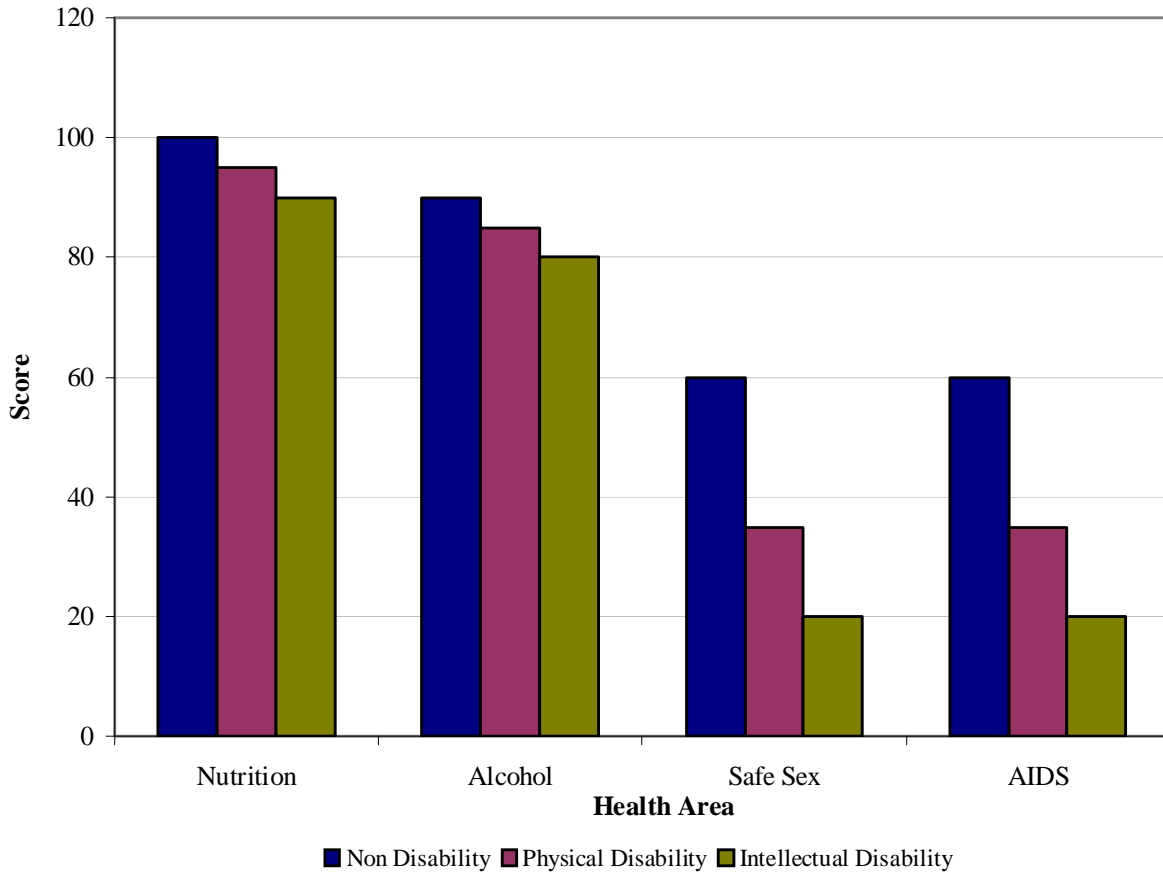
From the literature review it seems highly probable that the health knowledge of young people with disabilities would be improved if they were allowed to experience their social environment in similar ways to their non-disabled peers. For instance, lower levels of health knowledge among young people with physical disabilities of average or above average intelligence, cannot be explained away by differences in cognitive functioning. Consequently, to investigate the relative influence of cognitive functioning and social exclusion on health-related knowledge and motivations, three groups of young people were compared, those with i) no disability, ii) an intellectual disability, and iii) a physical disability, but with no cognitive impairment.

As the goal of this comparison study is to identify outcomes that are attributable to the unique factors associated with having an intellectual or physical disability, the effects of other potential confounding factors need to be controlled through matching during participant selection (Seltzer et al., 2004). This is discussed further in section 6.1.

5.1.2 Sources of Information: Public versus Private Health Topics.

Public health messages are widely available concerning topics such as healthy eating. For example, the five-a-day message regarding fruit and vegetable consumption is very much in the public domain. In contrast, information regarding sexual health is less available and is likely to rely on access to both formal and informal sources of information, ranging from health professionals to the exchange of information with peers. Hence, as people with intellectual and physical disabilities have greater difficulty accessing health professionals and often have impoverished social networks, they might be expected to have greater knowledge gaps in such private health domains. The sensitivities that surround HIV/AIDS make it difficult to discuss or access information around this topic. Moreover, it is a conceptually difficult topic to grasp, requiring some biological understanding of HIV as a virus. In addition, young people may not perceive themselves vulnerable to contracting HIV/AIDS, consequently attending to health messages less. It may be expected then that all young people will have knowledge gaps regarding HIV/AIDS, but again this will be most pronounced for young people with disabilities.

At the same time, it is acknowledged (and discussed in chapter 4) that social exclusion can have an impact on many areas of an individual's life, including development of social skills and adaptive behaviour. In most Western societies drinking alcohol is normal behaviour and is associated with social and cultural events. However, people with disabilities may experience less autonomy and have fewer opportunities to participate in their community. Social exclusion may prevent young people having access to social situations where alcohol is consumed, and therefore they may not gain experience and knowledge in alcohol related situations in the same way as their non-disabled peers (Kloep et al., 2001). Consequently it is hypothesised that alcohol knowledge will be poorer for young people with disabilities, albeit, this will not be as marked as for sexual health. Figure 5.1. offers a visual representation of this hypothesised relationship between health topic, social exclusion and knowledge.

Figure 5.1: An illustration of the hypothesised direction of health knowledge scores

5.2 Aims and objectives of Phase I

The main aim of phase one was to explore differences between adolescents with and without disabilities in relation to their health knowledge and understanding in two ‘public’ health topics (healthy eating and alcohol use) and two ‘private’ health topics (pregnancy/contraception and HIV/AIDS). In addition, it was hoped to examine the association between key features of social exclusion - social networks and access to sources of health information - in the development of health knowledge in these areas.

The specific objectives of phase 1 were to explore whether there are differences between young people with (i) no disability, (ii) an intellectual disability and (iii) a physical disability, but no cognitive impairment, in the following areas:

1. Knowledge and levels of understanding in relation to healthy eating, alcohol use, pregnancy/contraception, and HIV/AIDS.
2. The perceived sources of this health knowledge.
3. The opportunities they have to develop intimate relationships with others (their social networks).

Also explored were associations between participants' health knowledge and i) their perceived sources of support and ii) their social networks.

5.3 Methodological Justification

In phase I of this study a mixed methods design was adopted, incorporating both structured and open-ended methods. Significant time was allocated to developing and piloting appropriate methods and materials that would fulfill the aims and objectives of the study, and which were suitable for the sample population.

Over the last few decades, there has been a continuing debate in the social sciences about the superiority of quantitative methods over qualitative methods and vice versa. Quantitative methods adopt a positivist approach that views social behaviour to be governed by laws similar to those of physical science (Jones, Blair et al., 1998). Discovering the laws that govern human behaviour, through scientific study and observation, allows behaviour to be predicted and controlled. It is assumed that an objective reality exists and that this is separate from the individual being studied. As such, inquiries should be objective and free from potential biases, keeping a distance between the investigator and the investigated (Holloway and Wheeler, 2002). In contrast, interpretivists or qualitative researchers argue that people's experiences are socially constructed and context-bound. Therefore meanings, values and

commitments, often controlled for in quantitative research, are an integral part of the research process for qualitative researchers (Holloway and Wheeler, 2002). It is argued that in order to develop an understanding of human experience, rather than to try and predict and control behaviour, behaviour cannot be separated from its context (Crossley, 2000). As such complete objectivity is not possible.

In actuality, quantitative and qualitative research might be considered the ideal ends of a continuum along which actual research takes place. In health research, there has been a recent surge of interest in combining both quantitative and qualitative methods in single studies, this is known as mixed methods. It has been suggested that increasing popularity of such mixed methods is a result of addressing complex research questions relating to human health and well-being (O’Cathain, Murphy and Nicholl, 2007). Onweugbuzie and Leech (2004) advocate mixed methods as a third research paradigm, arguing that it allows the “combining of methods that have complementary strengths and non-overlapping weaknesses” (p.771). These authors illustrated how the collection, analysis and interpretation of qualitative data can facilitate the interpretation of significant findings in quantitative studies, and vice versa. In addition, the inclusion of quantitative data may help to compensate for lack of generalisability of qualitative data (Onweugbuzie and Leech, 2004). Hence, mixed methods are hoped to increase confidence in findings.

There were several specific reasons for adopting mixed methods with this study. In chapter 2 the limits of existing research methods that have been used in the area of health were highlighted. Various interview formats have been employed in eliciting children and young people’s health related knowledge and views, ranging from multiple-choice, self-administered questionnaires to semi-structured interviews and focus groups. Whereas closed-ended questions are advantageous in that they allow data to be collected with ease and increase response rates to questions of either a difficult or sensitive nature (i.e. sexual health), they tend to explore concepts and facts in isolation. As such, they tell us little about the nature of children’s thinking and beliefs about these matters. Although an accumulation of facts will enable individuals to respond to questionnaires, such knowledge will have limited value if it does not allow individuals to reason sensibly about behaviours beyond the educational setting (Au et al., 1999). Questionnaires may also include concepts that are not relevant to young

people and therefore are at risk of failing to adequately assess their knowledge. For example in chapter 2 evidence was presented showing that children do not spontaneously group foods using the same classification systems as experts (i.e. into sugars, fats, proteins). Even when participants are able to provide 'correct' responses to closed questions, the relevance of assessing this knowledge to everyday reasoning is sometimes questionable. Relying on quantitative methods alone can therefore lead to the overestimation of an individual's level of understanding and fail to identify misconceptions.

In response to the limitations of quantitative studies, other researchers have used qualitative techniques to tap into children and young people's understandings of health, for example through semi-structured questionnaires or focus groups (e.g. Schonfeld et al., 1993; Sigelman et al., 1999). However, as much as quantitative methods run the risk of overestimating knowledge, qualitative methods risk underestimating abilities, for example less verbal or younger individuals might struggle to express their views. The difficulty therefore lies in developing methods that adequately access this knowledge, and a combination of quantitative and qualitative methods may be the solution. In this thesis, it was decided that mixed methods would be the best research paradigm to adopt as the two methods could function as complementary components and help to provide insight into the content and depth of participants' health understanding.

A sequential mixed method approach was used, whereby the structured questionnaire was administered first, and after preliminary analysis of the quantitative data, one to one interviews were carried out. The rationale for this order was to use the questionnaire to introduce participants to the research in a relatively unthreatening manner, helping to build rapport with the researcher, as well as using this data to inform the development of the semi-structured interviews. Whilst it is usual for open-ended questions to be used at the initial stage of questionnaire design, it was thought that to begin with the open-ended discussion of sensitive and private health matters, such as sexual health, would be too threatening.

5.4 Study approval and ethical issues

5.4.1 Ethical Approval

Ethical approval for the study was granted from Greater Glasgow Community and Primary Care Local Research Ethics Committee prior to the recruitment of the participants. As a member of the British Psychological Society, the researcher also adhered to the ethical guidelines of this professional body. The main ethical considerations are detailed in the following section.

5.4.2 Ethical Issues

Informed consent - One of the main ethical issues was ensuring informed consent for participating in the research was obtained, particularly as the sessions were recorded. The first issue surrounding consent was applicable to all participants. As the interviews took place in school or college settings, care had to be taken to ensure that participants did not feel pressurised to participate in the study, particularly if they had been asked by their teacher/lecturer. To help avoid this, it was emphasised to potential participants that the research was independent of their school or college, and clearly stated that any information provided would be treated in confidence. The exception to this was disclosure of abuse or similar circumstances, where breaking confidentiality was a necessity. This was made clear prior to interview and again at the point of any disclosure. One participant disclosed abuse, however this instance was in the past and had been dealt with at the time (e.g. police had been involved). Additionally, a list of resources (books, leaflets and the names of organisations) was compiled for participants requesting further information on the interview topics.

With regard to young people with disabilities, there was the additional ethical issue of whether participants understood the nature of the research they were agreeing to participate in. It has been argued that the brief descriptions used to explain research are often inadequate, as people with intellectual disabilities are usually unfamiliar with the concept of research and what it involves:

“It is one thing to consent to the one-to-one aspects of research – that is, consent to talking to an individual researcher – and it is quite another to consent to the hidden, or behind-the-scenes, aspects of research – that is, the researcher going away with your answers, analysing them, coming to conclusions about you and your situation (which you may not even understand, much less agree with) and then informing others what they have discovered about you and people like you”. (McCarthy, 1999. p.104).

Therefore, the rationale for the study was explained clearly, including how it was hoped that the findings could benefit other young people, and what would happen to the findings. Although participants in the current study had a mild intellectual disability and were capable of expressing their own views and opinions, the information sheet that explained the research was produced in an accessible and symbolised format.

A third ethical issue that needed to be considered was the fact that the questionnaires and interviews addressed some very sensitive and emotive issues, particularly the sexual health sections (although participants were not required to provide information about their own behaviour). To address this concern, the topics covered in the interviews were guided by national documents giving advice on sex education in Scottish schools (see section 6.8.1) and through discussions with teachers and lecturers. In addition, where the respondent appeared to be uneasy or distressed, probe questions were not used. A substantial amount of time was allocated to developing sensitive and effective methods for addressing these potentially difficult topics with participants (see section 6.8).

The interviews were recorded with the participants’ consent on the basis that only the interviewer, would listen to the interview and that the full written transcript of the interview would be seen only by the researcher and her supervisor.

Right to withdraw - Interview participants were informed that they did not have to answer a question if they did not wish to, and that they had the right to withdraw from the interview at any point.

Anonymity - The main investigator was the only person to have access to participants’ demographic information. In order to maintain anonymity all participants were allocated an identification number and this was used in all interviews and questionnaires. All of the

interview transcripts were transcribed into an anonymous written format and any information that could identify the participants (such as names, locations and identifying speech idiosyncrasies) was removed from the data. Transcripts were identified only via the unique identification number, and information linking the sources and identification numbers were securely stored separately from the transcripts.

Confidentiality - All questionnaires, the coding system information and consent forms were kept separately in a secure lockable filing cabinet to protect confidentiality. Participants' demographic information was held in a password protected computerised database and the questionnaire responses were stored in a separate password protected database that contained no personal details about the respondents.

Debriefing - At the end of the interview, several minutes were spent debriefing the interviewee to ensure that s/he had not experienced any harm answering any questions. The majority of participants made additional comments at this time about the experience of taking part in the interview and asked how the data was to be used. Comments made at this point were not included in the results. In addition, it was verified that the interviewee had a contact phone number and email address so that s/he could get in contact if they had any further queries that might arise.

In addition, observations made during the interviews suggested that although a few participants became embarrassed whilst discussing certain topics, in particular sexual intercourse, none were sufficiently embarrassed to want to terminate their interviews and at no point was it deemed necessary to terminate the interviews without the participants' consent. Discussions with tutors and teachers suggested that participants were not anxious or distressed after participation and that overall participants reported the interview being a positive experience.

A copy of the information sheet and consent forms given to the participants can be found in Appendix B.

5.5 Recruitment

Participants were recruited from further education establishments throughout Glasgow. With regard to young people with intellectual disabilities, colleges that offered Supported Learning Courses were identified. Letters containing information about the study were sent to colleges and were followed-up a week later. Of the colleges that expressed an interest in the study, an oral presentation describing the research was given to the staff and/or students. Students who expressed an interest in participating in the study were then given information packs and consent forms to take away and discuss with their teachers/family. After two weeks the colleges were again contacted and interested students were given the opportunity to ask questions about the research and sign the consent forms.

It was not possible to recruit all the sample of students with physical disabilities through further education colleges and therefore a Special Educational Needs School in Glasgow was approached. Approval was gained from Glasgow City Council to conduct research within educational establishments and the same process outlined above was followed. All schools and colleges were mixed gender and non-denominational. Details on recruitment of the experimental groups are displayed in table 5.1 and figure 5.2 shows a flow chart for the recruitment of study participants.

The age group of 16 – 21 years of age was chosen for a number of reasons: young people at this age experience numerous transitions (i.e. educational, work) and as such may find themselves in new social situations with increased independence. It is also a time when adolescents may begin to experiment with and establish their own identities. Talking to these young people will enable us to develop a detailed understanding of young people's own theories in relation to health, which can be used to inform education strategies that are sensitive and relevant for a younger age group.

Table 5.1: Recruitment of Groups

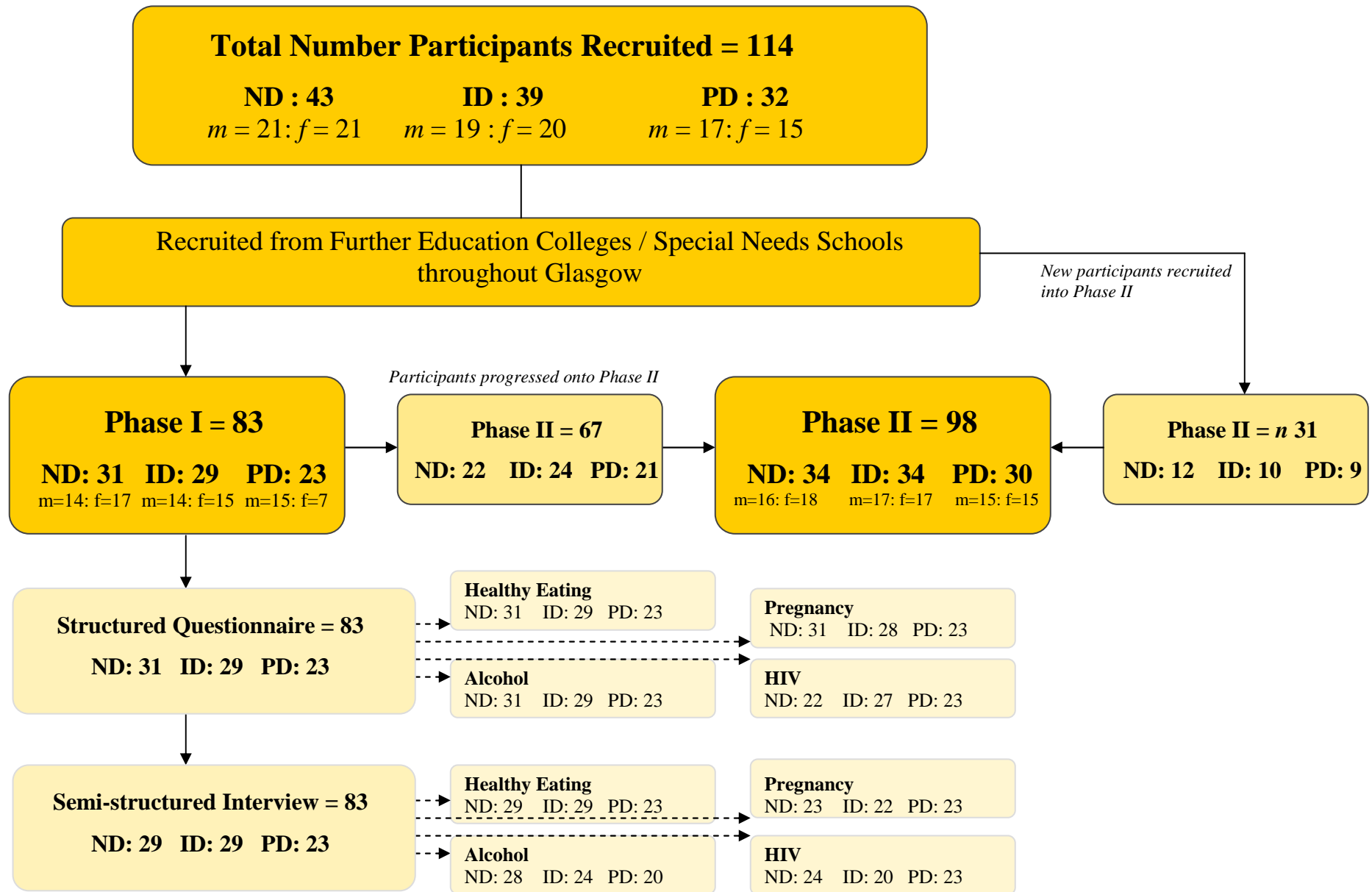
Group 1: No Known Disability (ND)
IQ score over 84 and no known disability. <i>The majority of participants had IQ scores in the 90's, with only two participants scores falling below 90. All participants in this group attended mainstream further education colleges in Glasgow and were enrolled on a wide variety of courses including engineering, chemistry, drama, childcare, and beauty therapy.</i>
Group 2: Mild Intellectual Disability (ID)
IQ score of 55-70 and no physical disability. <i>All participants in this group attended further education colleges in Glasgow and were enrolled on Supported Learning Courses, which included options such as core skill, life skills, supported work skills, personal and social education, art, drama, cookery and home skills.</i>
Group 3: Physical Disability (PD)
IQ score of over 70 and no intellectual disability. <i>The type of physical disability varied quite considerably as illustrated in table 2. All participants in this group attended a Special Educational Needs School in Glasgow.</i>
Group 4: Physical Disability (with a mild intellectual disability)
<i>Participants in this category met the criteria set out for group 3 above, but they had an additional mild intellectual disability, defined as having an IQ score of 50-70.</i>
Group 5: Borderline Intellectual Disability
<i>Participants in this category were the same as group 2 above, but they had a borderline intellectual disability, defined as having an IQ score of 70-84.</i>

5.6 Research setting

Scotland is often referred to as the sick man of Europe and within Scotland, Glasgow and the West of Scotland is viewed as having some of the worst health statistics in Europe. Although not the only factor, deprivation is one of the key causes of Scotland's poor health status (Scottish Executive, 2004) and socio-economic status (SES) is an important factor in relation to health related behaviours and health knowledge. Therefore demographic information such as home postcodes was collected to identify the participants' SES using the Carstairs Index (Carstairs and Morris, 1991).

The Carstairs Index is a frequently used measure of deprivation based on area of residence and was specifically developed for analysing Scottish health data. The Carstairs Index uses four indicators of deprivation (male unemployment, proportion of all persons in household where head of household is social class IV or V, overcrowding and car ownership) to create

Figure 5.2: Flow Chart shows Recruitment of Participants into Phases I and II



composite score. This score is divided into seven separate deprivation categories (DEPCAT). DEPCATs range from 1 to 7 and the higher the score, the higher the level of deprivation.

5.7 Sample size

The aim was to recruit participants into both phases of the study where they would be asked to complete the structured questionnaires and the one to one interviews.

The current research is a preliminary investigation since relationships between health knowledge, social networks and sources of information have not been previously analysed in young people with and without disabilities. Therefore the current power calculation is based upon the most relevant data available.

Power calculations for this study have been conducted using: i) McCabe's (1999) study comparing the sexual knowledge, experience and feelings of people with mild intellectual and physical disabilities and non-disabled individuals; ii) McCusker et al's (1993) study which explored alcohol-related knowledge and attitudes in people with a mild learning disability and their non-disabled peers and iii) pilot data from the healthy eating knowledge questionnaires. At a significance level of 0.01 and at a power of 0.8, the maximum number required for group 1 (ND) is calculated to be 20, for group 2 (ID) the number is calculated to be 32, and for group 3 (PD) the number is calculated to be 34. Therefore, the target sample size for the current study will be three groups of 30 participants. Power was calculated using the UCLA website power calculator (<http://calculators.stat.ucla.edu>).

5.8 Development of the Research Measures

In order to explore the impact of social exclusion, an instrument was required that would allow comparisons of health knowledge and understanding across the three groups of young people (individuals without disabilities, with intellectual disabilities, and with physical disabilities). Secondly, the instrument needed to allow health knowledge and understanding to be compared across two 'public' health areas (healthy eating and alcohol) and two 'private' health areas (pregnancy/contraception and HIV/AIDS). Thirdly, methods were needed that would allow

the exploration of both key health facts/messages and also an in-depth exploration of health understandings. Finally, the instrument was also required to permit the associations between health knowledge and understanding and i) sources of information and ii) social networks to be explored. The following sections describe the development and piloting of the research measures used in Phase I. This has been divided into two parts: part 1 deals with the structured questionnaire exploring health knowledge and sources of information, as well as the semi-structured interview examining participants' social networks; part 2 deals with the semi-structured interview exploring participants' health understandings and misunderstandings.

5.9 Part 1: Health Knowledge, Sources of Information, and Social Networks

5.9.1 Interviewing People with Intellectual Disabilities

As discussed in section 5.4., there are a number of strengths and limitations in using structured questionnaires to explore health knowledge. Although there has been an increase in the use of self-report measures for people with intellectual disabilities, there are a number of considerations and challenges that affect the reliability and validity of these measures. This becomes even more pertinent when researching a potentially private and sensitive topic like sexual health, particularly if individuals have had limited experience in discussing this previously.

Many of the health questionnaires that have been developed for the general population may not be suitable for people with intellectual disabilities, owing to difficulties with understanding and expressive abilities. Such difficulties may have ramifications for how a question should be asked, the participants' ability to respond to a question and the method by which responses are collected (Dockrell, 2004). Vocabulary and meaning should be kept clear and simple, avoiding complex sentence structures, avoiding the use of passive tenses, negatively worded questions, and using single clause sentences (Booth and Booth, 1994; Finlay and Lyons, 2001).

There have been particular concerns with the use of closed questions (e.g. yes/no, either/or questions) with respondents who have intellectual disabilities. In particular, there is a view that closed questions will increase the likelihood of acquiescent responses, or the tendency to say 'yes' to a question irrespective of content (Sigelman et al., 1980, 1981). Studies have shown that acquiescence is more marked in people with intellectual disabilities and increases with degree of intellectual disability (Sigelman et al., 1981). According to Shaw and Budd (1982) this is due to an inability to understand the question or how to answer it, resulting in the respondent falling back on the strategy of providing a positive answer in an attempt to please the interviewer. However, studies finding an increased tendency to acquiesce in this population have been challenged. It has been argued that the kinds of questions asked in these studies were more likely to generate uncertainty and doubt in respondents (Simons, Booth and Booth, 1989).

Heal and Sigelman (1995) reported that either/or questions were less prone to systematic response bias than yes/no format, although the former could introduce a different type of response bias caused by the recency effect where the last option presented is selected (Prosser and Bromley, 1998). Using pictures with either/or questions have been demonstrated to be useful in increasing responsiveness and understanding (March, 1992; Sigelman and Budd, 1986) as well as reducing response biases caused by the recency effect (Heal and Sigelman, 1995).

Likert-type scales are increasingly used in the field of intellectual disability research. Likert-type scales typically require the respondent to indicate their level of agreement with a series of statements. It has been suggested that as the respondent is required to distinguish between subtly different statements (i.e. 'some of the time', 'often' and 'always'), many participants with intellectual disabilities are unable to respond appropriately (Hartley and Maclean, 2006). Hartley and Maclean (2006) reviewed 51 studies that had used Likert-type scales with adolescents and adults with intellectual disabilities. They reported that overall Likert-type scales had comparable response rates with yes/no, either/or questions, and open-ended questions. However, there was evidence of low response rates and response biases, such as participants choosing the most positive response alternative, in some of the studies. To increase reliability and validity of these measures, the authors offered several suggestions.

Firstly, Likert-type scales had better reliability and validity when used with adolescents or adults with borderline or mild intellectual disabilities. Secondly, pictorial representations may help to distinguish between response alternatives. Thirdly, pre-tests should be conducted, either to identify and remove respondents who are unable to respond reliably, or to determine the complexity of the Likert-type scales to be used. Pre-tests can also be used to train participants in using Likert-type scales, thus decreasing response bias. For example, training participants to distinguish among response alternatives and providing them with feedback on how to use them. Fourthly, brief descriptors of the response alternatives such as ‘none’, ‘a little’, ‘medium’, ‘a lot’ worked best as they required the respondent to understand differences between a limited number of simplified response alternatives. Using scripted prompts may be beneficial to help clarify items. Finally, up to five different response alternatives could be used without reducing the response rates, although Hartley and Maclean (2006) suggest that this is best determined through piloting as it depends on the individual’s experience with the behaviour in question.

In considering the advantages and limitations offered by different question formats and the specific research questions of phase I of the study, a mixture of both questions with multiple-choice and Likert-type scale response formats were used to assess health knowledge, sources of information and social networks.

5.9.2 Health Knowledge, Sources of Information and Social Network Questionnaires

5.9.2.1 Health Knowledge Questionnaire

Questionnaire content was guided by previous research, existing questionnaires, health education curricular guidelines, current health policies, and health websites (table 5.2). These sources were reviewed for young people with and without disabilities to ensure the questionnaire was accessible and relevant. In other words, care was taken to ensure the content reflected common health messages to which all groups had been exposed, thus allowing comparisons to be made across groups. In addition, this helped to make sure the terminology

used within the questionnaire corresponded to that commonly used in health promotion messages.

Within Scottish schools, there are guidelines on structure, content and assessment of the health education curriculum, although schools are not legally required to follow these guidelines (www.ltscotland.or.uk). Guidelines such as the Health Education: 5-14 National Guidelines (Learning and Teaching Scotland) and The Health Education for Living Project (HELP; Learning and Teaching Scotland, 1998) were reviewed and helped inform the questionnaire content. As the manner in which schools and colleges operationalise health education curricular guidelines may differ, interviews were first conducted with staff involved in health education from the young people's school/college to ensure instruments were appropriate.

There are a number of policy documents, supporting papers and initiatives in each of the health areas that were used to help develop the questionnaire by ensuring the topics covered met with current government guidelines/initiatives (www.healthscotland.com, discussed in chapter 1). Finally, health websites for young people were examined, again to ensure the content and terminology used within the questionnaire was appropriate (table 5.2.).

Table 5.2: Health Information Websites

Various Health Topics www.healthscotland.com www.takelifeon.co.uk www.youngscot.org	Sexual Health www.ruthinking.co.uk www.playingsafely.co.uk www.likeitis.org/indexuk www.healthyrespect.org.uk www.cklearn.org.uk	<div style="display: flex; align-items: center;"> <div style="width: 15px; height: 15px; background-color: #800080; margin-right: 5px;"></div> Scottish Website </div> <div style="display: flex; align-items: center;"> <div style="width: 15px; height: 15px; background-color: #000080; margin-right: 5px;"></div> British Website </div> <div style="display: flex; align-items: center;"> <div style="width: 15px; height: 15px; background-color: #008000; margin-right: 5px;"></div> Website for people with ID </div>
Healthy Eating www.eatwell.org.uk	HIV/AIDS www.avert.org	
Alcohol www.talktofrank.com www.infoscotland.com/alcohol		

After reviewing these sources and establishing the areas that the questionnaire should address, the initial pool of items was created. The potential items were discussed with colleagues with clinical and research expertise in intellectual disability and health psychology in terms of content, wording and relevance to the research questions. After narrowing down the item pool,

a final set of questions remained that could be piloted on young people with and without disabilities to check the usability and acceptability of the questionnaire and to identify any ambiguous questions.

5.9.2.2 Sources of Information Questionnaire

During the literature search, several studies that had explored participant's sources of information in relation to health were reviewed. Andre et al. (1991) examined young peoples' perceived sources of sex education in greater detail than other studies. In their study, participants were required to rate the percentage of their total sex education they had received from 14 potential sources (i.e. mother, father, friends, church). The participants were then presented with a list of 35 different sexual health topics. For each topic they were asked to rate on a five point scale how much information they had received from a predefined list of five sources. Although this study presented rich data on sources of information, such a measure would be far too repetitive and laborious in the current study, particularly as four health areas were being explored. A questionnaire was needed that would explore perceived sources of health education in sufficient detail, yet was concise enough to ensure participants remained engaged in the interview. Therefore, a shorter list of potential sources was developed, guided by previous research. This relevance and usefulness of the predefined list of sources was explored in the piloting stage, alongside the value of also including open-ended questions.

5.9.2.3 Social Network Semi-Structured Questionnaire

The aim of this section was to explore young peoples' social networks, focusing on peer interactions. A semi-structured questionnaire framed around the participants' daily activities over a 'typical' week was piloted. As many participants with intellectual disabilities have problems dealing with questions regarding time and frequency, this allowed questions to be anchored in daily routines. By structuring questions around the week, and discussing daily activities in a systematic manner, it was hoped that a description of the participants' leisure time activities would be produced.

5.9.3 Key Issues Addressed In Piloting

The questionnaires were piloted with eight young people, four of whom had an intellectual disability, one a physical disability and three with no known disability. The main aim of this pilot was to check the usability and acceptability of the questionnaires and the visual stimuli, and to ensure interviews were relevant and engaging.

5.9.3.1 Health Knowledge Questionnaire – Content

The initial stages of the questionnaire development were exploratory. Participants were first presented with open-ended questions and their responses used to narrow down and redefine the initial item pool. This data also allowed the way participants interpreted the questions to be explored and their responses were used to help determine the response alternatives to the multiple-choice questions and Likert-type scale response categories. As the response alternatives came from participants themselves, this ensured they were relevant and meaningful.

As a result of the piloting, some questions were removed to shorten the questionnaire and some questions worded differently to reduce ambiguity and maximise clarity. Questions that produced a high non-response rate (i.e. ‘don’t know’) that appeared to be misunderstood by participants, or where participants requested further information were removed or reworded. Some questions also appeared too wide in scope and, as such, had to be narrowed down or supplementary questions/probes added. For example when asking how likely it would be that eating lots of biscuits/cakes/sweets would lead to someone gaining weight or developing heart disease, several participants said that this depended on factors such as the frequency and duration of the behaviour and whether the individual engaged in any physical activity. Similarly, with alcohol, several participants mentioned factors such as whether an individual had eaten or not when assessing the likelihood of becoming intoxicated and vomiting or suffering memory loss. Therefore, additional information was provided, such as the quantity of junk food / alcohol consumed and whether the behaviour was a ‘one-off’ or maintained in the long-term. For the sexual health questionnaires, additional information also had to be

provided, for example, whether protection was used during sexual intercourse or not, or whether gloves were worn when handling needles or dealing with cuts.

Several questions, particularly in the sexual health section had to be removed, as they were too abstract for participants in the ID group. For example, using terms such as sperm or ova produced a low response rate with participants. These questions were overly biological and therefore were not appropriate for this section, as the aim was to explore knowledge of key health facts.

5.9.3.2 Questionnaire Format

Providing participants with the question and response alternatives may influence how the question is interpreted and affect the response given (Oppenheim, 1992). For example, closed questions tend to cue respondents and instead of using their own words to respond to questions, they must fit an answer to a series of pre-assigned categories. This was another important consideration with the questionnaire, as visual stimuli were used to illustrate the questions. Therefore, different ways of presenting the questions and visual stimuli were experimented with, for example exploring whether it was best to present the questionnaire and all the response alternatives together, or to present the question first, followed by each of the response categories. The latter approach worked the best, as it helped to break down the question and reduce memory load.

Changes were made to the order of the multiple-choice questions as a result of piloting to avoid participants falling into a particular response set, such as saying ‘agree’ or selecting the last option. To ensure that the multiple-choice questions did not influence responses given to the Likert-type scale questions, the order the measures were administered in was altered, with half of the participants completing the multiple-choice questions first, and the other half of the participants completing the Likert-type questions first.

5.9.3.3 Sensitivity of the Visual Stimuli

It has been suggested that using pictures to represent options may help to enhance the reliability of participants’ answers. A participant’s understanding of a word may be different

to that of the interviewers, or of other young people. There is evidence, for example, that children who have word finding difficulties may have slightly different representations of words or use words differently, and this may also be true for people with intellectual disabilities (Dockrell, 2004). For example, during piloting when participants were asked about the healthiness of ‘meat’, it became apparent that participants were thinking about different types of meat to one another, i.e. lean versus fatty, processed versus fresh, white meat versus red meat. This is an important distinction, as these different types of meat have different health-related qualities. Therefore, one advantage of using visual stimuli was to ensure that the questions conveyed similar meanings across the three groups of participants. As people with disabilities may experience difficulties with memory and concentration, using pictures may have helped reduce the memory load when participants were asked to attend to multiple response items and make the interview more engaging.

Throughout the pilot interviews participants were asked questions about the photographs/illustrations to ensure they accurately represented the response options and that they were relevant to the young people. Piloting highlighted that some photographs/illustrations failed to represent the concept in question and in light of the comments made by participants, particularly with more complex and abstract questions in the sexual health sections, new photos or illustrations were used. An example of this was with a photograph of the male condom. When shown a photograph of a condom rolled up, several participants failed to recognise what it was. However, recognition was increased when illustrated through several photographs, such as in a packet, rolled up and unrolled.

5.9.3.4 Engagement with Instruments

Inclusion of active tasks, such as getting participants to ‘post’ their responses into a box and using card-sorting tasks proved valuable. Participants appeared to engage well with the interview process as evidenced through their enthusiasm when selecting the response options, with several participants explicitly stating that they enjoyed the ‘hands-on nature’ of the interview. Focusing participants’ attention on these active tasks helped to maintain participants’ motivation throughout the interview and reduced his/her feelings of

embarrassment or a lack of confidence in their own abilities when dealing with sensitive topics.

With regard to the visual stimuli, participants would make comments about the pictures such as *'wow, that's got loads of fat in it, I wouldn't eat that'* or *'that's really risky'*, indicating that the photographs were relevant, useful, and absorbed participants into the interview. Comments from the participants also demonstrated that they enjoyed the interviews and materials, and liked having the opportunity to talk about health issues and the feeling that they were contributing to the research.

5.9.3.5 Sources of Information Questionnaire

During the piloting phase, open-ended questions were used to explore where participants accessed information for each of the four health topics, healthy eating, alcohol, pregnancy/contraception and HIV/AIDS. Participants provided information on the sources they had accessed to obtain information for quite general issues, such as information about healthy/unhealthy foods, as well as for more specific issues, such as weight or diet. This information was used to create a list of predefined sources of information to be used in the questionnaire, alongside a general open-ended question.

It became apparent that it was necessary to include a predefined list of sources, as several participants with intellectual disabilities did not respond to the open question. Visual stimuli were used to illustrate the predefined sources of information, and throughout the pilot interviews participants were asked questions about these illustrated sources to ascertain their usefulness and relevance. As with the other sections, participants were observed to see how they responded to the questionnaire and visual stimuli. It was noted that for some participants the questionnaire become a bit repetitive, therefore in the main interviews if participants' concentration started to waiver, follow up questions were used to check responses.

5.9.3.6 Social Network Semi-Structured Questionnaire

During the piloting of the social network questionnaire, it became apparent that visual stimuli would be useful in prompting participants' responses. Examples that were piloted included

pictures of leisure activities such as watching television, shopping and talking to friends and these were included in the main questionnaire.

Subsequent versions of all the instruments were piloted and further modifications made. Following this, the final instrument was piloted with three young people with intellectual disabilities and no further changes were made.

Copies of the final questionnaires and visual stimuli can be found in Appendices C & D.

5.9.4 Final Instrument Developed from Piloting

The final instrument consisted of four main sections. Section 1 and 2 concerned data regarding young people's knowledge about healthy eating, alcohol, pregnancy/contraception, and HIV/AIDS. Section 1 consisted of questions with multiple-choice response formats and section 2 used Likert-type scale response formats. Section 3 concerned data on participants' sources of information and section 4 covered social networks. Table 5.3 provides a breakdown of each section and scoring.

5.9.4.1 Section 1: Multiple-Choice Questions – Health Knowledge

For each of the four health topics (healthy eating, alcohol, pregnancy/contraception, and HIV/AIDS) there were eight questions in a multiple-choice format; three questions adhered to an agree/disagree/not sure format, and five questions had three response alternatives to choose from. The aim of this section was to explore participants' knowledge of key facts about healthy eating, alcohol, pregnancy/contraception, and HIV/AIDS. The questionnaire assessed the facts that young people had accumulated about a health topic but did not necessarily require respondents to have any depth of understanding of the phenomena in question. For example, an individual may know what foods are unhealthy (i.e. 'eating too much fried food is bad for your health'), without knowing why ('eating too much fat may lead to the build up of plaque that can clog up the arteries'). Similarly, an individual may correctly respond to a questionnaire item asking if condoms can prevent pregnancy, but still have a very limited understanding of sexual intercourse. The rationale for choosing the multiple-choice format and visual stimuli for section 1 of the questionnaire has been described above (section 5.3). As

stated previously, visual aids are useful in questionnaires and it is important that these are relevant to the individuals being interviewed and this was achieved through carefully piloting the measures. Using the example of healthy eating, it would be misleading to include food items that participants are unfamiliar with. In the study by Noble and her colleagues (2003), photographs of foods typically served in the participants' school cafeteria were used to explore understanding of healthy eating, making the task relevant and authentic to children's experiences. Therefore, in section 1 a high quality colour photograph was used to represent each response alternative. Response options for each question were attached by Velcro onto an A4-sized page and participants were required to 'post' their selected response into a box (Turk and Burchell, 2003). The act of selecting and posting the response was used to engage the participant in the interview, increasing the accuracy of the data collected as well as making the interview enjoyable for the participant. At the beginning of the interview, participants were presented with several 'trial' questions, to ensure they understood what they were required to do and were provided with feedback and corrected if necessary. Questions varied in level of difficulty to ensure that participants who were more knowledgeable in a health area were able to demonstrate their knowledge. Questions in this section were scored as either correct or incorrect, giving a maximum score of 8 for the Alcohol and HIV/AIDS sections, and 9 for the healthy eating and pregnancy/contraception sections (see table 5. 3).

Each question within the four sections was considered as a stand alone item, rather than grouping items together. The reasons for this were that questions explored participants' awareness of key facts about healthy eating, alcohol, pregnancy/contraception, and HIV/AIDS, and as such covered their knowledge of various aspects of the health topic. Questions were also selected on the basis that they varied in level of difficulty and content area, to ensure that participants who were more knowledgeable in a particular health area were able to demonstrate their knowledge. As such grouping items would not have been appropriate nor would it have provided a better interpretation of the data.

As discussed in section 5.1.2. the processes by which we learn about private health topics, like sexual health, may be quite different to how we learn about other health matters. Much education about sex-related matters is gained through informal routes, such as sharing sexual knowledge and attitudes with peers (Cole and Cole, 1993). Individuals who have limited

opportunities for peer contact could also have their sexual development hindered. Therefore, to further our understanding of the barriers that young people with disabilities face when learning about sexual matters, the four subscales were analysed separately (healthy eating, alcohol, pregnancy/contraception, and HIV/AIDS), as opposed to summing the scores to give an overall indication of health knowledge.

Table 5.3: A Description of the Subscales, Content Areas and Range of Scores for the Health Knowledge, Sources of Information and Social Networks Questionnaires

Questionnaire	Format	Content Area	No. Items	Range of Scores
Section 1: Health Knowledge	Multiple-choice (32 items)	Healthy Eating:	8	0-9
		Alcohol:	8	0-8
		Pregnancy & Contraception:	8	0-9
		HIV/AIDS:	8	0-8
Section 2: Health beliefs	Likert-type Scales (32 items)	Healthy Eating:	8	0-32
		Alcohol:	8	0-32
		Pregnancy & Contraception:	8	0-32
		HIV/AIDS:	8	0-32
	Closed question	<i>For each health topic:</i>		
Section 3: Sources of Information		Family	1	0-1
		School	1	0-1
		Friends	1	0-1
		Health professional	1	0-1
		Media	1	0-1
Section 4: Social Networks	Semi-structured interview	<i>No. Friendships:</i>		
		within school/college	---	---
		external to school/college	---	---
		<i>Frequency of:</i>		
		activities with peers	---	---
		family based activities	---	---

5.9.4.2 Section 2: Likert-Type Scale - Beliefs about Health Effects

For each of the four health topics, the types of misconceptions participants held in relation to healthy eating, alcohol, pregnancy/contraception and HIV/AIDS were explored. This section was based on a method successfully used by Sigelman et al. (2000) to explore children's beliefs about alcohol and cocaine use. Participants were presented with a series of health-related behaviours and asked to rate how likely they thought a given outcome would occur.

For example, how likely is it that you would get AIDS from kissing someone who had AIDS? Participants were asked to rate each statement as not at all likely, a bit likely, quite likely, or very likely. As suggested by Hartley and Maclean (2006), descriptors of the response alternatives were kept brief and the number of alternatives offered was limited to four and this worked well during piloting. Visual stimuli were used to illustrate the behaviour, the health outcome, and the response alternatives. All participants were first presented with a pre-test.

For each health topic there was a list of eight health-related behaviours, four of the outcomes were correct and four were incorrect. The item scores ranged from 1 (not at all likely) to 4 (very likely), with a response of 'don't know' being scored as 0 and scores being reversed for the incorrect health outcomes. Thus, for each health topic the maximum score was 32 (see table 5.3). However, although the health outcomes such as disease, pregnancy or HIV infection, may be more likely to occur if an individual engages in a specific behaviour, they are not an inevitable result of engaging in the behaviour. For example, the individual who consumes a high fat, high sugar diet may be increasing his risk of developing heart disease; however other factors such as genetics, exercise, and co-existing health conditions modify this association. Therefore, this section assessed participants' perceptions of risk and scores could only be used to indicate how strongly each participant endorsed an outcome. As such, although an average score was computed, no formal statistics were applied to the data and analysis remained descriptive.

For each health topic, the eight health-related behaviours can be further divided into two different dimensions. For healthy eating, four items examined possible health outcomes associated with consuming a diet high in fruit/vegetables and four items examined possible health outcomes associated with consuming a diet high in fat/sugar. For alcohol, four items examined long term health outcomes associated with drinking and four the short term effects. For both pregnancy/contraception and HIV/AIDS, four items examined true risks factors for pregnancy or HIV transmission, and four items false risk factors. Evidence suggests that young people's understanding differs across these health dimensions. For example, young people are more knowledgeable about unhealthy food than they are healthy food (Noble et al., 2000, 2003) and are better at describing positive exemplars of how HIV is transmitted than

they are at rejecting myths (Sigelman et al., 1993). As such, data were examined for differences across these areas, although as stated above no formal statistics were applied.

The questions used in the multiple-choice and Likert-type scales varied in complexity. For example, items assessed participants' awareness of highly publicised health messages, such as the link between an unhealthy diet and heart disease or unprotected sex and HIV. However, to allow participants with a more sophisticated health understanding the opportunity to demonstrate this, items that assessed participants' awareness of less commonly known facts, such as the association between alcohol and mouth disease, or that the fact that HIV cannot be transmitted through a swimming pool, were also included.

5.9.4.3 Section 3: Sources of Information Questionnaire

After completing sections 1 and 2 for each health topic, information was collected regarding sources of information participants reported using. Participants' spontaneous sources of information were elicited first via an open-ended question. This was followed up by a series of structured questions. The open-ended question allowed participants to discuss their most salient sources of information and ensured that any potentially important sources were not overlooked. Examples from the health knowledge questionnaire were used to frame the open-ended question, for example. *"We have just talked about alcohol and you told me about how drinking alcohol can affect your behaviour and can damage your body. Where did you find out about this? Who have you spoken to about these things?"* This helped to ensure that when recalling the sources of information accessed, all participants were thinking of similar aspects of the health topic. In addition, providing concrete examples helped participants to recall where they got information from. Once the participant had named a source, they were probed for further details to ensure the validity of the source, for example *"you said you spoke to your friends about alcohol, who was that? Was it someone at this college? What did you talk about?"*

Following the open-ended question, participants were presented with a list of five potential sources of information (family, school/college, friends, health professional, and media) and asked if they had ever used these. Again, probes were used to elicit further information on each named source. The structured questions acted as an aide-mémoire, as participants may

have accessed a source yet failed to recall it when asked via the open-ended question. Visual stimuli were used to illustrate the predefined sources. The number of participants in each group who reported having used the pre-defined sources for each health topic was noted.

5.9.4.4 Section 4: Social Network Questionnaire

After completing the sources of information questionnaire, participants were asked about their social networks. The interview began by asking the participants about what they did on each day of the week, for example who they met during the day, what activities they engaged in (i.e. at break and lunch periods at school/college), how they got home, what they did after school/college, who they saw at weekends and so forth. The main data extracted from the semi-structured interviews were: i) number of friendships within school or college, ii) number of friendships continued outside of, and/or external to, school or college, iii) number of activities engaged in per week with family members, and iv) number of activities engaged in per week with peers. Items three to five (iii – v) were restricted to activities which took place outside of the school/college.

It was important to include a measure exploring both friendships within school/college, and those that were continued or formed outside of school or college, as it may be argued that it is informal networks which provide support for sharing private health knowledge and developing skills. It is acknowledged that although this was only an approximate guide to participants' social networks and leisure time activities, it allowed a rough estimate of how the participants' week was divided. Follow-up questions were used to ensure that activities mentioned were not 'one off' occurrences and to clarify and validate responses.

5.9.4.5 Wechsler Abbreviated Scale of Intelligence (WASI-II; Wechsler, 1999)

For the present study, participants' intellectual ability was ascertained using the two-subset form of the Wechsler Abbreviated Scale of Intelligence: Vocabulary and Matrix Reasoning subscales (WASI-II; Wechsler, 1999). The WASI is nationally standardized, and yields Verbal, Performance and Full Scale IQ scores. Correlations between the WASI and the WAIS-III are adequate (0.88 for Vocabulary, 0.66 for Matrix Reasoning). Adequate content validity,

clinical validity and construct validity has been demonstrated amongst intellectually disabled populations.

5.9.5 Data Entry and Analysis

To ensure participant confidentiality, two computerised password protected databases were set up; one database was set up in excel to record participant demographic characteristics, and the other in SPSS used for entering data on knowledge, sources of information and social networks. The quantitative data analysis was performed using SPSS 10.0 for Windows and is presented in chapters 6 of this thesis.

The Kruskal-Wallis one-way analysis of variance for independent groups was used to see if there were any significant differences between the groups in terms of IQ scores, Age, SES, and health knowledge. Where significant effects were found, pairwise comparisons were then performed using the Mann-Whitney test to identify where these differences lay.

5.10 Part 2: Semi-Structured Interviews

The quantitative component of the study provided data about participants' knowledge of key health facts in relation to healthy eating, alcohol, pregnancy/contraception and HIV/AIDS. The aim of the semi-structured interviews was to generate a detailed exploration of participants' understandings and misunderstandings of these topics. As such, the questions in the interview complemented material obtained from the structured questionnaire, and allowed participants to raise other relevant topics that were missed using the closed question format. The semi-structured interview was also guided by previous research and existing questionnaires (e.g. Galea et al., 2004; Kistner et al., 1996; McCabe, 1999; Schonfeld et al., 1993; Sigelman et al., 1999).

5.10.1 Developing the Semi-structured Questionnaire

Qualitative data can be generated in a number of ways including observation, case studies, in-depth interviews and focus groups. Interviews are commonly used in health research, for

example in exploring experiences, behaviour, feelings and knowledge (Britten, 2000). Although there has been a proliferation in the use of qualitative methods in health research (Harding and Gantley, 1998) there are a number of challenges in using this approach with people with intellectual disabilities. These challenges have frequently led to the perspectives of people with disabilities being excluded from research, relying instead on the views of the professionals or carers. As people with disabilities are often perceived to be poor communicators, then it is frequently assumed they cannot be 'good sources of quotable data' (Gillman, 1999. p237). Although interviewing any young person about sensitive topics like sexual health may increase the incidence of error and bias (Barnett, 1998), this may be more marked for young people with intellectual disabilities who may have limited previous experience in discussing sexual health matters. There is also a concern that these individuals will become too embarrassed or distressed during such interviews to be able to develop a meaningful dialogue (McCarthy, 1999).

However, it is the job of the researcher, to develop methods to overcome such barriers and allow the voices of people with intellectual disabilities to be heard (Booth and Booth, 1994). Qualitative research methods have been increasingly used with this population to explore matters including parenting (Booth and Booth, 1994) and sexuality (McCarthy, 1999). McCarthy (1999) successfully conducted interviews with women who have intellectual disabilities about their sexual experiences. Many of the women reported positive feelings about participating in the research, even with topics that were more difficult and distressing. With regards to fears of distress and embarrassment, Thomas and Stenfert Kroese (2005) investigated how young people with mild intellectual disabilities reacted both during and after their participation in quantitative sexuality research. They reported that none of the young people appeared anxious or distressed after the interview. Although some respondents were embarrassed during the interview, none of them felt sufficiently overwhelmed to require the interviewer to terminate the discussion.

Nevertheless, using open-ended questions with people who have intellectual disabilities does present difficulties that need to be addressed. Researchers who have used open-ended questions with this population have reported that participants often provide single word or short phrase answers (Booth and Booth, 1994). However, as McCarthy (1999) notes, this

phenomenon is not confined to people with intellectual disabilities. If a question is of a particularly sensitive or private nature, such as sexuality, then any group of individuals may be more reluctant or find it more difficult to provide a detailed response. To overcome the risk of minimal responses, a decision had to be made about how structured the interview should be. On the one hand, if it was too heavily structured it would make it difficult to explore individuals' own understandings of health. Yet if the interview format was too unstructured then there was a risk of obtaining minimal responses from participants. In an attempt to maximise the participants' ability to answer accurately, flexibility was allowed in the interview schedule. For example the vocabulary and sentence structure were altered depending upon the abilities of the participant and carefully constructed prompts and follow-up questions were used to aid the flow of discussion (McCarthy, 1999). Although McCarthy (1999) discusses the importance of repeating and rephrasing participants' responses, it is important not to do this too often in case it risks creating false responses, for instance by participants answering in a way they feel the researcher wants. With regard to question content there is the temptation to simplify questions in order to increase understanding, however if questions are oversimplified then there is the risk questions become meaningless and an accurate account of individuals' knowledge or beliefs is not obtained (Dockrell, 2004).

Building a rapport is one way to maximise response rate, particularly when enquiring about sensitive issues. It has been advocated that interviewing participants in their own homes is an effective way of establishing rapport, and if this is not possible, an attempt should be made to keep the research atmosphere informal (Booth and Booth, 1994; McCarthy, 1999). Before commencing the interview, the purpose was explained and participants were encouraged to ask questions about the interview process. The interviewer introduced herself as a researcher in an attempt to distance myself from other professionals that the young person may have contact with, including those within the college. Young people may perceive adults to hold negative attitudes and stereotypes towards young people and health related behaviours, and therefore care was taken to ensure that this did not influence the participants' responses. The fact that the interviews took place within the school or college setting posed the risk that the interviewer would be associated with figures of authority and could have increased the likelihood of obtaining socially desirable responses. To help counteract this, time was spent at the beginning of the interview establishing rapport with the interviewee and emphasising the

independence of the researcher from the school or college authorities. It was also made clear that the spirit of the interview was to find out what the young person knew, rather than what they did not know and to explore their views as experts on their own lives. It was also important to consider the impact of interviewer characteristics, such as gender, on the participants' responses. It was hoped that as the researcher was a woman in her twenties, it was advantageous for her to be interviewing young women about sexual matters. There was less certainty of the comfort of the young men being asked questions about private and sensitive matters by a female researcher. However, there has been evidence that sensitive questions may be less threatening when asked by a woman (Flores-Macias and Lawson, 2008). In this study, the researcher built her expertise in carrying out these interviews in the piloting phase. This opportunity to develop her self-confidence in dealing with this sensitive topic was crucial to helping overcome the male participants' embarrassment and to increasing their engagement in the interview process.

5.10.2 Key Issues Addressed In Piloting the Semi-structured Questionnaire

At the outset of piloting, there were several specific aims to ensure the appropriateness and validity of the final instrument. The first aim was to assess the suitability of the questions in terms of wording, length, and question structure, and ensure that they allowed a comprehensive assessment of understanding in each health topic. Secondly, as the aim was to assess and compare understanding in young people with and without disabilities, care was taken to ensure that all participants were given an equal opportunity to demonstrate their understanding. As this was to be achieved through the inclusion of verbal prompts, visual stimuli and various 'hands-on' activities, the piloting phase allowed these elements to be assessed in terms of their i) usefulness in eliciting information across groups, ii) meaningfulness to participants and iii) ability to engage participants in the interview.

5.10.2.1 Content and Format of the Semi-structured Questionnaire

There were some changes to the order of the interview. It became apparent during piloting that asking questions about negative aspects of health influenced participants' answers to

subsequent questions. For example, in relation to alcohol, if participants were first asked about the ways that alcohol might make someone feel bad, they often remained in a negative mindset. This led to them answering subsequent questions about positive aspects of alcohol use in a negative fashion and they may have been led to believe that this is what the interviewer wanted to hear. Therefore, all sections started with a neutral opening gambit, followed by a positive open-ended question.

The main changes to the instrument were in the pregnancy/contraception section. It was anticipated that this section would need some adapting after piloting, owing to a paucity of research evidence providing guidance in this area. For example, in asking young people what sexual intercourse is, participants may have been unable to answer this question, not because of a lack of knowledge, but because of the sensitive nature of the topic. The initial open-ended question was retained, even though many young people with disabilities were reluctant to answer this, at least in any detail. However, visual stimuli were introduced to help participants frame their responses. By presenting the outline of a male and female figure, participants were able to point to the parts of the body that they thought were involved in sexual intercourse. More often than not, after doing this, participants went on to name the body parts and give a more detailed response. Keeping the question open also allowed participants to respond using their own familiar terminology and allowed subsequent questions to be reworded to incorporate these.

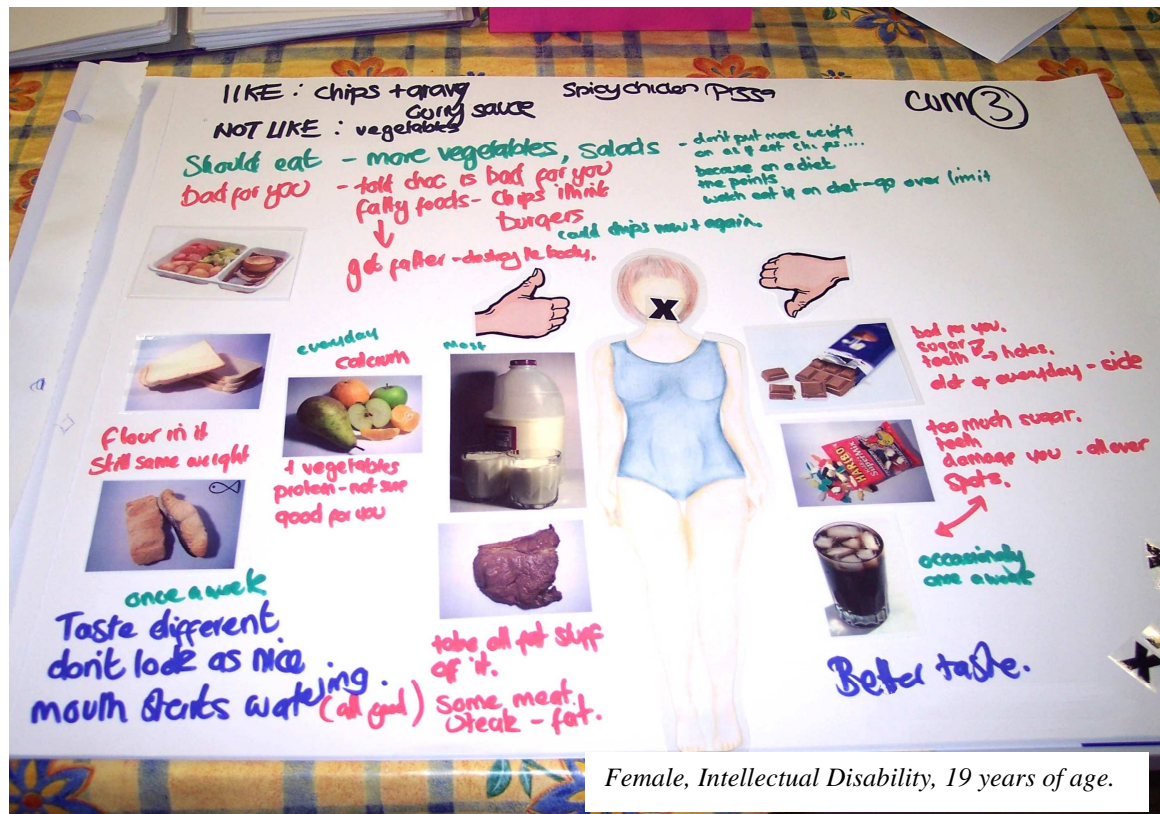
From the piloting a chronology was developed that gradually moved from relatively easy questions to those that were of a more sensitive nature. As each question built on the previous, participants were supported to present as much of their knowledge and understanding as possible. The questions followed a logical order, so they were not disjointed and remained meaningful to participants. For example, with the alcohol interview participants were asked to imagine that an individual drank some alcohol. They were then asked to describe where the alcohol would go in the body and what it would do to the body. Using structured prompts, such as '*what would alcohol do to (body part)?*' '*what would happen then?*', and '*what would happen next?*', in conjunction with visual stimuli helped to maximise the response rate. The piloting showed this approach to be very successful in eliciting knowledge and was well received by the participants.

5.10.2.2 Sensitivity of Visual Stimuli

As with the multiple-choice questionnaires and Likert-type scales, throughout the pilot interviews participants were asked questions about the photographs and illustrations to ensure they accurately represented the response options and that they were relevant to the young people. Piloting highlighted that some photos, particularly those in relation to behaviour (i.e. *alcohol can make you forgetful*) failed to represent the concept in question and new illustrations were created. Similarly, several card-sorting activities were piloted to obtain the optimal measure. During piloting it was noted that these tasks helped to maintain motivation throughout the interview and reduced the participants' feelings of embarrassment or lack of confidence in their own abilities. In the main interview an A1 sheet of paper was used to record participants' responses, both through writing their answers down and using the visual stimuli, to create a visual representation of the interview. This was a joint effort between the participant and myself and helped to link the different questions together, as well as allowing us to reflect on responses and clarify points of confusion. It also highlighted to the participant everything that they did know about a topic, ensuring they left the interview feeling positive about their abilities. This approach seemed very successful, with one female participant fetching her lecturer into the interview room to show him all the things she knew about health! An example of one of the interviews is shown in figure 5.3.

5.10.2.3 Engagement with Instruments

Finally, as with the quantitative section, observations were made on how participants responded to the questionnaire. Although it was apparent that participants did become slightly more embarrassed during the sexual health questions, overall they seemed to engage well in the interview, and more importantly enjoyed it. In particular, participants from all groups engaged most with the card-sorting activities, which seemed to distract from the interview being perceived as a 'test'. Again, participants appreciated being given an opportunity to express their views and opinions. Inevitably some participants were less positive and commented that the interview was simply a means of getting out of class for a while.

Figure 5.3: An example of the visual stimuli being used during a healthy eating interview

5.10.3 Final Version of the Semi-Structured Interview

For each of the four health topics, the interview began with an opening gambit or ‘ice-breaker’, for example asking participants about the types of foods they liked, if they liked to drink alcohol, and what they thought about the sex and relationship education they had received. The interview was divided into two main sections, which had a similar format across each of the four health topics being explored. The topics discussed are shown in table 5.4. All questions were illustrated by visual stimuli. Copies of the interview schedule and visual stimuli can be found in Appendices E & F.

In section 1, participants were presented with a series of open-ended questions about the health topic. Scripted prompts were then used to clarify or obtain further information if needed. This allowed participants to present their salient beliefs about each health topic and gave an opportunity to identify any misunderstandings.

Table 5.4: Semi-Structured Interview – Content Areas

Beliefs about healthy/unhealthy eating

Open-Ended Questions

- Perceptions of a healthy/unhealthy diet
- Beliefs about the effects healthy/unhealthy foods can have on the body

Card-Sort Task

- Classification of healthy and unhealthy foods
- Explanations for classifying foods as healthy/unhealthy

Beliefs about alcohol

Open-Ended Questions

- Beliefs about why people drink/positive aspects of alcohol use
- Beliefs about the negative aspects of alcohol use

Card-Sort Task

- Classification of possible outcomes/effects of alcohol consumption
- Understanding of how alcohol causes these outcomes/effects

Beliefs about Pregnancy and Contraception

Open-Ended Questions

- Understanding of pregnancy/reproduction
- Beliefs about contraceptives

Card-Sort Task

- Classification of risky and non-risk behaviours
- Understanding of how contraceptives work / rejection of myths around pregnancy

Beliefs about

Open-Ended Questions

- Beliefs about possible routes of HIV transmission
- Understanding of mechanisms of HIV transmission

Card-Sort Task

- Classification of risky and non-risk behaviours
 - Understanding of HIV causality / transmission
-

In section 2 participants were presented with several A5 cards with a colour photograph or illustration on it. Participants were required to sort these cards according to a given dimension (i.e. healthy and unhealthy foods, possible and impossible routes of HIV/AIDS transmission) by placing them under either a ‘thumbs up’ or a ‘thumbs down’ symbol. Participants were required to give a rationale for their decisions as they were executing the task. The section began with the participant being shown a colour illustration of a male and female body. For each health topic, they were given a different scenario that would frame the card-sorting activity. For example, in the healthy eating interview, the following scenario was presented:

“Here is a picture of a young man and a young woman. They want to be healthy and feel good about themselves. Which of those foods do you think they should try to eat? What is good about that food? Which foods do you think they should not eat? What is bad about that food?”

Follow-up questions were then used to assess what participants thought would happen to the individuals’ bodies if a diet was deficient in a food, or if a food was eaten in excess, and why. Participants were also given coloured stickers to mark on the picture of the body what body parts they thought would be affected, allowing them to demonstrate their knowledge without being dependent on verbal abilities.

Using the card-sorting activity and the illustration of the body allowed a comprehensive assessment of the participants’ health knowledge. These ‘hands-on’ tasks and visual stimuli not only helped to structure participants’ responses, but also allowed them to be actively involved in the interview. Similar scenarios were used for the alcohol interview (effects of alcohol on the body and behaviour), pregnancy/contraception (methods of contraception and myths about getting pregnant) and HIV/AIDS (risky and non-risky behaviours).

5.10.4 Recording and Transcription

The interviews were recorded using a SonyTMICD-MS525 digital recorder. Recording the interviews allowed me to concentrate on the interview and engage in appropriate eye contact and non-verbal communication. The interviews were fully transcribed. The interviews lasted, on average, for 47 minutes and ranged from 25 minutes to 54 minutes. Participants’ identities were protected because all of the participants and classmates, tutors or family members to whom they referred were assigned pseudonyms. In addition, place names were omitted from the transcripts (see section 5.4.2).

5.10.5 Analysis

Data was analysed using conventional content analysis (Hickey and Kipping, 1996; Hsieh and Shannon, 2005; Weber, 1994). Hsieh and Shannon (2005) defined content analysis as “a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns” (p.1278). As

discussed in section 5.10.3., the semi-structured interview was divided into two main sections and these were analysed separately.

5.10.5.1 Section 1: Open-Ended Questions

In section 1, participants were presented with a series of open-ended questions for each health topic. For each of these questions a list of categories and subcategories was created, derived directly from the participants' responses. Data was then quantified by counting the frequencies of these categories, allowing comparisons to be made across the three groups. The Computer Assisted Analysis of Qualitative Data (CAQDAS) package, NUD*IST was used to help manage the data, for example indexing and retrieving codes. The major categories identified and examples of coding for section 1 are displayed in table 5.5.

5.10.5.2 Section 2: Card-Sort Task

In section 2 participants were presented with a card-sorting task in which they were asked to give a rationale for each choice they made. For section 2, four separate coding schemes were developed to assess participants' understandings of healthy eating, effects of alcohol, contraception and HIV transmission. As with section 1, categories were developed directly from the transcripts, however, they were also guided by the theoretical framework developed by Perrin and Gerrity (1981). Perrin and Gerrity developed a coding scheme to explore children's understanding of illness causation, based on the stages in development of understanding of causality described by Piaget (1960). The scales are hierarchically organised into six response categories, with higher scores representing more sophisticated and abstract thinking about illness causation. The coding systems developed by Perrin and Gerrity were chosen because they offered a systematic method for describing the content of children's responses and are well-established and accepted, having been used previously in diverse health areas such as nutrition (Goldman, Whitney-Saltiel, Granger and Rodin, 1991), alcohol (Sigelman et al., 1999), smoking (Meltzer, Bibace and Walsh, 1984), and HIV/AIDS (Schonfeld et al., 1993). The coding systems do not directly reflect those used by these authors as it was felt more important to develop codes from the data itself, particularly as research exploring health understandings in people with disabilities is limited. However, utilising a wide range of studies to inform the coding system meant that the coding schemes maintained a

consistent framework across the different health areas, which permitted some comparisons of participants' understandings across health topics. The coding schemes are shown in table 5.6.

Following the development of a coding scheme, inter-rater reliability was computed. A second-rater was provided with a written description of the key characteristics of each category and randomly assigned eight transcripts to code. Any discrepancies identified were discussed until agreement had been reached with the code allocation or with modifications to existing codes. Item-by-item inter-rater agreement was determined by calculating the total number of agreements between the two raters' scores for each item, dividing by the total number of agreements and disagreements, and multiplying by 100. The percent inter-rater agreement was as follows:

Healthy Eating	%	Alcohol	%
Section one:	93	Section one:	92
Section two:	89	Section two:	98
Pregnancy/contraception		HIV/AIDS	%
Section one:	95	Section one:	92
Section two:	91	Section two:	93

Throughout the stages of data collection, the interviews were reflected upon, for example making sure that leading questions were not being used, particularly with less verbal participants. This followed through into the analysis stage, where it has been suggested that researchers are at increased risk of impressing their own subjective interpretations on the data when participants have lower verbal abilities (Goodley, 1996).

Table 5.5: Example Coding from Section 1 of the Semi-Structured Interview

Beliefs about a Healthy and Unhealthy Diet	
Which of those foods should you should try to eat/try to avoid eating?	
Name specific food item: <i>"You should eat lots of fruit"; "Try not to eat too much chocolate".</i>	
Name food group: <i>"Eat lots of fibre"; "Not a lot of fat, you shouldn't eat fat".</i>	
What is good/bad about that food?	
Name health benefit/consequence: <i>"It's good for the heart"; "It's going to make you fat".</i>	
Diet Composition	
Moderation: <i>"You should have some fat, a little bit is good for you"; "As long as you don't have too much".</i>	
Variation: <i>"Bits of everything"; "Something from each food group".</i>	
Natural vs. Processed foods: <i>"Stuff that's fresh and not got lots of additives".</i>	
Beliefs about the Health Effects of Alcohol Consumption	
Can you think of some things that alcohol does that would make you feel good/bad?	
General health effects: <i>"It just damages everywhere, all of your body".</i>	
Specific health effects: <i>"It goes to your liver"; "It damages the heart".</i>	
Non-health related outcomes: Positive - <i>"makes you feel good, have a good time"</i>	
Negative - <i>"you'd get real angry".</i>	
Beliefs about Pregnancy and Contraception	
How someone would get pregnant/make a baby?	Score
Mention the following:	(6)
(a) the erect penis	
(b) is inserted into the female's vagina	1
(c) whereupon stimulation experienced during sexual intercourse	1
(d) sperm is released.	1
The sperm then (f) travels inside the female in order to meet with the ova,	1
which (g) if the conditions and timing are right, will be present.	1
What could they do to stop them making a baby/getting pregnant?	1
Name a form of contraception/abstinence: <i>"They could use a condom".</i>	
Beliefs about the HIV/AIDS	
How would someone get HIV/AIDS?	Score
Routes of transmission: <i>"You get it from sex"; "If you share needles".</i>	(6)
Mechanisms of transmission - mention the following:	
(a) HIV must be present,	1
(b) in sufficient quantity,	1
whereupon it must (c) get into the body in order	1
for it to d) enter the bloodstream and replicate.	1
(e) HIV can also only survive under certain very specific conditions.	1

Table 5.6. Description of Coding Schemes

Healthy Eating	Alcohol Effects	Contraception	HIV Transmission
<p>Level 1 Don't know, circular, magical or global response Participant cannot explain his/her response, restates the question or mentions phenomenon associated with the behaviour.</p>	<p>Vague catastrophic consequences of alcohol. Inevitably the consequence of drinking alcohol are catastrophic and are universal (happens to all who drink). It's a concrete and observable event and there is no explanation except beyond the mere co-occurrence of two events.</p>	<p>Participant cannot explain his/her response, restates the question or mentions phenomenon associated with sexual activity/behaviour. There is no attempt to provide a causal link between contraceptive use and outcome.</p>	<p>Participant cannot explain his/her response, restates the question or mentions phenomenon associated with having HIV as if it were its cause. There is no attempt to provide a causal link between the event and the outcome.</p>
<p>Level 2 Isolated Facts & Concrete rules Stereotyped responses and the repeating back of rules, with no understanding of them</p>	<p>Nutrient Content of Food Participant refers to an inherent healthy or unhealthy quality of the food, for example fat, protein, sugar, yet is unable to offer any explanation of how this interacts with the body, e.g. "Lots of salt"</p>	<p>Quantity, speed, duration or content Where an effect is attributed to the amount of alcohol ingested, the speed at which it is ingested, or the time period over which it has been taken OR the content of the alcoholic beverage, such as 'chemicals', 'acid' or 'gases'.</p>	<p>Casual contact or contagion Concrete, specific, isolated causal agents/ actions are named, but does not mention agents must get into body/act upon body in particular way, nor what the causal agent does or why, e.g. "You get it from sex". May overgeneralise from knowledge of other illnesses.</p>
<p>Level 3 Generalised Principles or Effects Participant begins to mention resultant effects on the body, although with no mention of how it interacts with the body to produce an effect.</p>	<p>Global Effect on Organ Participant mentions a specific effect on an organ or the body, yet offers no explanation to how, e.g. "It's good for your bones"</p> <p>Global Effect on Organ Participant refers to how alcohol damages the organ or body as a whole, but there is no explanation of damage, e.g. "by getting into your liver-you drink it and it goes to your liver"</p> <p>Effect on Brain Participant acknowledges the role of the brain in producing the specific effect, yet cannot articulate how, e.g. "The brain, some of the alcohol, affects your brain cells"</p>	<p>Isolated agents Participant begins to discuss how the contraceptive affects internal agents or body parts, such as sperm, eggs, penis, vagina, hormones, but with little understanding of how they interact within the body, e.g. "it's got hormones in it".</p>	<p>Bodily Fluids Participant mentions high-risk bodily fluids, however fails to mention agents must get into body/act upon body in particular way, nor what the causal agent does or why (i.e. knowledge appears to be rote), e.g. "you get it from needles, if you touch the blood".</p>

Table 5.6. continued over

Table 5.6: Continued

	Healthy Eating	Alcohol Effects	Contraception	HIV Transmission
<u>Level 4</u> Specific Action or Effect One effect on an internal organ and at least one change in behaviour/outcome and specific causal link. No mechanism of how specifically the agent interacts with the body is articulated.	Link Between Content and Organ Participant is able to describe both the inherent healthy or unhealthy feature of the food and links this with a specific effect on the body, e.g. ““It has fat, which is bad for you heart. It gives you heart attacks”.	Link Between Alcohol and Organ Participant describes specifically how or why an organ is damaged or involved in producing the effect, but does not mention the brain. Responses include one effect on an internal organ and at least one change in behaviour and specific causal link, e.g. “Alcohol gets into your liver and makes it all black. They get real sick. Sometimes they get cancer”.	Biological Mechanism Participant is able to discuss the biological mechanism which stops pregnancy, e.g. “The hormones, they stop you having a period, and you can’t get pregnant then”.	Internalisation of the Agent Participant begins to describe the internalisation of the agent. The causal agents act on the body or get into the body and do something specific to the body, e.g. “You put a dirty needle into your arm and you get AIDS”
<u>Level 5</u> Physiologic Processes and Mechanisms A coherent mechanism or process within the body explaining the action or effect is given by the participant to explain how the causal agent/action interacts with, on, or in the body to cause the specific outcome. Responses are more expanded, differentiated and physiological effects described in greater detail.	Specific Link Between Content and Organ As above, but the participant is able to give a specific and detailed explanation, e.g. “Fat damages your arteries and stops the blood flowing properly, that’ll cause a heart attack”	Specific Link Between Alcohol & Brain Participant is able to articulate the central role that the brain plays in producing alcohol effects, e.g. “Your eyesight and your back of the brain are all connected, and your brains affected and that will affect your eyes”	There was no level 5 for contraception understanding	Internalisation into Bloodstream Participant understands that the internalisation of high-risk body fluids is necessary for transmission, for example into bloodstream, e.g. “You put the dirty needle into your arm, and then the AIDS goes into your blood, and you’re got AIDS”.

5.11 Procedure

Interviews were arranged for participants who consented to the study via their teachers/lecturers. All participants were interviewed within the school/college. Before the interview commenced, the purpose of the interview was explained to the interviewees and they were encouraged to ask questions if they were unsure about the interview process. All measures were administered orally on a one to one basis, in a quiet, undisturbed room. Participants were seen over two to three sessions. In the first session, the health knowledge questionnaire was administered, with each subscale being followed by the sources of information questionnaire. At the end of session one, social network data was collected. In the second session, the semi-structured interview was administered. For both the structured and semi-structured interviews, the healthy eating section was always introduced first, followed by the alcohol, pregnancy/contraception, and HIV/AIDS sections. This was to facilitate the building of rapport. By introducing a topic that is unthreatening and relatively easy to discuss at the beginning of the interview, the individual is able to build up their confidence in answering the questions and it gives the opportunity for a rapport to be established between the participant and interviewer. To avoid the interviews being perceived as a test-like situation, the Wechsler Abbreviated Scale of Intelligence (WASI), used as an assessment of intellectual functioning, was administered at the end of the interview. It is acknowledge that IQ scores are not the only feature of having an intellectual disability, so in addition, discussions with staff identified potential participants (see section 5.5). As discussed in section 5.4., at the end of the interview several minutes were spent debriefing the interviewee to ensure that s/he had not experienced any harm answering the questions and asked participants if they would like to add any further comments

Chapter 6: Phase I Quantitative Data: Health Knowledge

The aims and objectives of the study were outlined in the previous chapter and this chapter will focus on the quantitative component of the study. Descriptive information will be provided about the participants who completed the structured health questionnaire and by comparing data across the three groups of young people, the differential impact of cognitive ability and social exclusion will be examined.

6.1 Participants' Demographic Characteristics

Ninety-six young people aged from 16-25 participated in the first phase of the study, of which 31 had no known disability, 36 had a mild/moderate intellectual disability and 29 had a physical disability. At interview and upon examination of the data it was noted that several participants from the physical disability group also had mild intellectual disability and a small proportion of the intellectual disability group had a borderline intellectual disability. To be able to explore the differential impact of social exclusion and cognitive impairment upon health knowledge and understanding it was important to ensure that the physical disability group did not have an intellectual disability. Therefore a conservative approach was taken and all those with physical disabilities who had IQ scores above 70 were analysed separately. In addition, participants with a borderline intellectual disability were also analysed separately. The groups are shown in table 6.1. This chapter is concerned with groups one to three only; participants without a disability, those with a mild/moderate intellectual disability, and those with a physical disability, but no intellectual disability.

It should be noted that for the physical disability (no intellectual disability) group some of the participants did have borderline disabilities. However, when the knowledge scores were examined there were no significant differences across any of the scales and thus scores were similar enough for these two groups (physical disability with borderline intellectual disability and physical disability with no intellectual disability) to be collapsed. Amalgamating the data from these two groups is further justified by the fact that the instrument used to assess IQ (the Wechsler Abbreviated Scale of Intelligence, WASI; see

Table 6.1: Classification of Groups

Group 1: No disability (n = 31)
IQ 84+
And no known disability
Group 2: Mild/Moderate Intellectual Disability n = 29)
IQ 55-70
And no physical disability
Group 3: Physical Disability (n = 23)
IQ < 79 and any combination of the following:
Asthmatic*
Brain Tumor
Congenital abnormality
Conradi Hunermann Syndrome
Cerebral Palsy
Epilepsy
Friedrichs Ataxia
Head injury (acquired Cerebral Palsy)
Hearing impairment*
Motor disorder
Myalgic Encephalomyelitis
Muscular Dystrophy (congenital)
Myotonic Dystrophy
Neurofibromatosis
Neuromuscular Condition
Spina bifida
Speech impairment*
Visual Impairment*
*Participants with these disabilities also had another disability
Group 4: Physical Disability and Mild Intellectual disability (n = 6)
IQ 55-70
And a physical disability
Group 5: Borderline Intellectual Disability (n = 7)
IQ 70-84
And no physical disability

section 5.9.4.) has intrinsic disadvantages for those people with physically disabilities and other factors may have also masked their true abilities. For example, although for the current study, having a visual or hearing impairment was not a criterion for inclusion into the physical disability group, many participants with physical disabilities did experience visual and hearing difficulties. Individuals with visual impairments may have been disadvantaged on abstract and spatial assessments, whereas individuals with hearing impairments may have been disadvantaged on verbal reasoning tasks such as the vocabulary scale. Other factors such as chronic pain and fatigue may have reduced some young people's concentration (Heller et al., 1996; Lord, 2007). Consequently, the IQ scores for young people in the PD group, as measured by the WASI, may not have reflected their true abilities and one might expect a higher level of error relating to these scores. Lord (2007) provides guidance on good practice in using psychometric assessments with people with disabilities, suggesting that the same test norms as for non-disabled

populations should be used but that it may be more appropriate to use two standard errors of measurement rather than one. It is emphasised that an individualistic approach to test interpretation is needed for this population.

Table 6.2: Participants' Demographic Characteristics

Group	No Disability	Intellectual Disability	Physically Disability	
	<i>n</i> 31	<i>n</i> 29	<i>n</i> 23	
Male	14	14	16	
Female	17	15	7	
IQ Scores			Unadjusted Score	Adjusted Score
Mean	97.1 ^a	59.41 ^b	92.7 ^c	95.7a [†]
Median	97	56	92	95
Range	84-109	55-69	79-105	82-108
SD	5.7	5.24	6.6	6.6
Age				
Mean	18.90 ^a	18.59 ^a	16.74 ^b	
Median	19	18	17	
Range	16-25	16-22	16-18	
SD	1.97	1.59	0.75	
SES				
Mean	4.68 ^a	5.14 ^a	4.61 ^a	
% 1-2 (Affluent)	16.1	13.8	13.0	
3-4	25.8	17.2	30.4	
5-7 (Deprived)	58.1	68.9	56.5	
Ethnic Group				
White	<i>n</i> 31	<i>n</i> 29	<i>n</i> 22	
Asian	<i>n</i> 0	<i>n</i> 0	<i>n</i> 1	
Living Arrangements				
Family Home	<i>n</i> 26	<i>n</i> 27	<i>n</i> 23	
Independently	<i>n</i> 5	<i>n</i> 0	<i>n</i> 0	
Supported accommodation	<i>n</i> 0	<i>n</i> 2	<i>n</i> 0	

For IQ scores, age and SES (socio-economic status), means that do not share a superscript in common are significantly different from each other. [†] These scores have been adjusted by two standard errors of measurement.

The variables used to define and match groups one to three are displayed in table 6.2. These included participant's IQ score, age, gender, race/ethnicity, living arrangements, and socio-economic status (SES). As discussed in section 5.5, the non-disabled and intellectual disability groups were recruited from further education establishments throughout Glasgow. The physical disability group was recruited mainly from secondary schools in Glasgow. Unfortunately this meant that physical disability group was younger than the non-disabled and intellectual disability group. It was not possible to collect data on

participant's educational history (i.e. transitions from mainstream to special school/college or vice versa). In addition, whilst every attempt was made to match participants on gender this was not feasible. Together, this may have impacted upon the degree compatibility across the three groups, which should be kept in mind when interpreting the results.

Eighty-three participants formed the three main groups, of which 31 had no known disability (ND), 29 had an intellectual disability (ID) and 23 had a physical disability (PD; table 6.3). All participants completed the healthy eating and alcohol questionnaire, 82 the pregnancy/contraception questionnaire and 81 the HIV and AIDS questionnaire. The reasons for participants not completing all four of the questionnaires were unavailability at follow-up because they had left college and, for the HIV questionnaire, one participant stated they had never heard of HIV or AIDS and therefore was unable to complete the subsection. All missing data was from the ID group.

6.1.1 Participants' Intelligence Quotient Scores, Age and Socio-Economic Status

In the following section IQ scores (as measured by the WASI), Age and Socio-economic status (SES) are examined for the three groups. As data deviated significantly from normality, non-parametric tests were employed. The Kruskal-Wallis one-way analysis of variance for independent groups was used to investigate if there were any significant differences between the groups in terms of IQ scores, Age and SES. Pairwise comparisons were then performed using the Mann-Whitney test to explore where any differences were. As multiple statistical tests were conducted on the data, to control for type 1 errors (the decision to reject the null hypothesis when it is, in fact, true) the modified Bonferroni procedure (Jaccard and Wan, 1996) was employed. The modified Bonferroni is said to be more appropriate than the classical Bonferroni method as it is less likely to produce type I and type II errors (failing to reject the null hypothesis when it is, in fact, false). The modified Bonferroni procedure works as follows: the significance values obtained from multiple tests are rank ordered from smallest to largest. The significance of the test with the smallest p-value is evaluated at $\alpha / \text{number of tests}$ (as in the classical Bonferroni procedure). If the test is statistically significant the next test is evaluated at $\alpha / (\text{number of tests} - 1)$. If this test statistic is significant evaluate the third test as $\alpha / (\text{number of tests} - 2)$. This continues with all tests until a non-significant result is obtained.

As expected the non-disabled group had the highest IQ score (median = 96), followed by the physically disabled group (median = 92), with the intellectually disabled group scoring the lowest (median = 56). Differences between the three groups were significant ($\chi^2(2) = 58.134$; $p = 0.001$) and pairwise comparisons showed there to be significant differences between the IQ scores of all three groups (ND-ID, $z = -6.686$; $p=0.001$, ND-PD, $z = -2.129$; $p=0.04$, PD-LD, $z = -6.195$; $p=0.001$). The subtest and scale scores of the WASI have average standard errors of measurements of about three points (Strauss, Sherman and Spreen, 2006). If we apply the two standard errors of measurement, as has been suggested for people with physical disabilities, this would mean participants in the PD group could have a true IQ score ± 6 points of the observed score (the true IQ of participants would be ± 3 points of the observed score). Therefore, IQ scores of participants in the PD group were adjusted upwards by three points to make comparisons across the groups equal. Once scores had been adjusted, the difference between the ND and PD groups in terms of intelligence was no longer significant ($z = -0.552$; $p=0.6$).

Groups also differed by age ($\chi^2(2) = 28.577$; $p = 0.001$). The physically disabled group had a medium age of 17 and were significantly younger than both the non-disabled group (median age of 19; $z = -4.798$; $p=0.001$) and the intellectually disabled group (median age of 18 = $z -4.634$; $p=0.001$), owing to the fact many of the participants were recruited from schools rather than further education colleges.

The sample was predominately deprived with 58.1%, 68.9% and 56.5% of the ND, ID and PD groups respectively, living in DEPCAT 5, 6 or 7 (table 6.3). There were no significant differences in SES across groups ($\chi^2(2) = 2.667$, $p = 0.27$).

6.2 Health Knowledge

The structured questionnaire consisted of two main sections: section 1 used multiple-choice questions and section 2 used Likert-type scales. As discussed in section 5.9.4, formal statistics were applied to data derived from the multiple-choice questions only; analysis for the Likert-type scales data was descriptive.

The Kolmogorov-Smirnov test and normal Q-Q plots confirmed that data deviated significantly from normality. Neither the removal of outliers or the transformation of the data through using natural logs or square roots resulted in normally distributed data, hence

non-parametric tests were used. To explore any differences in knowledge between young people with and without disabilities in the four health areas, the Kruskal-Wallis One Way Analysis of Variance for independent groups was used. This was followed by Mann-Whitney test to establish where any differences were, again using the modified Bonferroni procedure for multiple tests of significance.

6.2.1 Between-Group Differences in Health Knowledge and Beliefs about Health Outcomes

The summary scores for the three groups are displayed in table 6.4 and 6.5. Descriptive data is provided on participants' main understandings and misunderstandings for each section, highlighting any interesting or unexpected trends. As some responses were endorsed by only a few participants, numbers are mainly presented here.

In addition, for the Likert-type scales, as discussed in section 5.8.2., it is perhaps more informative to look at the distribution of these scores than the average. Therefore, the percentage of responses in each category (i.e. not at all – very likely) for each group were examined and trends highlighted (see appendix D for graphs on the distribution of responses). Data was also examined for gender differences in relation to health knowledge, although such differences were mainly found in the ND group, as the males and females in the ID and PD groups performed similarly across scales.

As described in sections 5.1. and 5.2., it was hypothesised that the fewest differences in health knowledge would be seen across health topics that are in the public domain; healthy eating and alcohol. However, owing to less autonomy and access to social situations where alcohol is consumed, it was hypothesised that the differences between groups would be more apparent in relation to alcohol. With regard to topics in the public domain, such as sexual health and HIV, it was hypothesised that young people with intellectual and physical disabilities would have greater knowledge gaps than their non-disabled peers, as a result of their poorer access to sources of information and impoverished social networks. The findings in relation to each of these hypotheses are discussed below.

Table 6.3: Participants' Health Knowledge Scores – Multiple-Choice Questions

	No Disability	Intellectual Disability	Physically Disability
Subscale			
Healthy Eating			
Mean	7.45 ^a	6.69 ^b	7.13 ^a
Median	7	7	7
Range	5-9	4-8	4-9
SD	1.2	1	1.0
Alcohol			
Mean	6.77 ^a	5.62 ^b	6.48 ^a
Median	7	6	6
Range	5-8	3-8	5-8
SD	1.1	1.2	0.8
Pregnancy/contraception			
Mean	8.32 ^a	6.04 ^b	6.74 ^b
Median	9	6	7
Range	6-9	3-9	4-9
SD	0.9	1.6	1.4
HIV/AIDS			
Mean	7 ^a	4.5 ^b	6.35 ^a
Median	7	5	7
Range	5-8	2-7	4-8
SD	0.9	1.2	1.3

Means not sharing the same subscript are significantly different from one another

Table 6.4: Participants' Beliefs about Health Effects - Likert-Type Scales

	No Disability	Intellectual Disability	Physically Disability
Subscale			
Healthy Eating			
Mean	27.8 ^a	26.1 ^a	27.5 ^a
Median	28	26	28
Range	22-32	17-32	23-32
SD	2.7	3.5	2.8
Alcohol			
Mean	27.9 ^a	26.5 ^b	28.8 ^a
Median	28	27	29
Range	23-31	20-31	23-32
SD	2.1	2.6	2.3
Pregnancy/contraception			
Mean	25.4 ^a	21.4 ^b	23.0 ^b
Median	26	22	24
Range	2.5	4.5	3.2
SD	20-29	12-31	17-28
HIV/AIDS			
Mean	27.7 ^a	23.8 ^b	26.4 ^a
Median	28	24	27
Range	22-32	16-31	19-32
SD	2.0	3.5	3.2

Means not sharing the same subscript are significantly different from one another

6.2.2 Healthy Eating Knowledge

6.2.2.1 Multiple Choice Questions

As shown in table 6.3, although all three groups had a median of score of 7 on the healthy eating scale, differences between the groups were significant ($\chi^2 = 11.090$; $p=0.004$). As predicted, pairwise comparisons showed that this was due to the ID group being less knowledgeable than either the ND ($z = -3.137$; $p=0.002$) or the PD group ($z=-2.175$; $p=0.030$), who in turn performed similarly to one another ($z = -1.193$; $p=0.233$). Data tended to be negatively skewed, with participants generally scoring at the higher end of the scale. This was most marked for the ND group for whom 6 participants (19.4%) achieved the maximum score, compared to 1 participant in the PD group and none in the ID group.

Overall, young people were quite knowledgeable about healthy eating and as was expected, group differences were minimal. There were however a few interesting findings. The majority of young people in the ID group and a large proportion of the PD group found the concept of ‘moderation’ difficult; only one participant in the ID group and 13 participants (56.5%) from the PD group knew that just eating salad would be unhealthy.

This was compared to 28 participants (90.3%) in the ND group. There were also a few misunderstandings evident across the three groups. For example seven participants in each group believed that meat and fish should be consumed more frequently than fruit and vegetables. Another interesting finding was that eight participants in the ND group believed that eating bread and potatoes would cause you to gain more weight than eating biscuits (as compared to one participant in the PD group and none from the ID group).

6.2.2.2 Beliefs about Health Outcomes

As table 6.4. illustrates, there were few differences across the groups in terms of endorsing true health outcomes or rejecting false outcomes associated with diet, although the ND and PD groups tended to score higher (medians = 28) than the ID group (median = 26). There was a trend across groups for participants to be clearer about how the body is affected by ‘junk’ food than how it is affected by healthy foods. For example, a larger proportion of participants’ responses to items exploring the negative health outcomes of an unhealthy diet were coded as *very likely*, than were for positive health outcomes associated with a

diet high in fruit and vegetables (70-75% versus 48-59%; see appendix D). The majority of participants in each group believed that eating large amounts of 'junk' food was *quite likely* or *very likely* to cause damage to teeth (ND: 30, ID: 25, PD: 21) and weight gain (ND: 29, ID: 27, PD: 23). However, fewer participants believed a diet rich in fruit and vegetables would be *quite likely* or *very likely* to help prevent illnesses like the cold and flu (ND: 19, ID: 9, PD: 8) and several participants in each group believed this would be *not at all likely* (ND: 7, ID: 9, PD: 8). Participants were better informed about the relationships between a healthy diet and heart disease, with 21, 23 and 19 participants in the ND, ID and PD groups respectively, believing that a diet rich in fruit and vegetables would be *quite likely* or *very likely* to help to keep the heart strong.

6.2.3 Alcohol Knowledge

6.2.3.1 Multiple Choice Questions

As shown in table 6.3. the ND group were the most knowledgeable about alcohol (median = 7), followed by the PD group and the ID group whose median scores on the alcohol subscale were 6 ($\chi^2 = 14.841$; $p = 0.001$). As expected, the ND and PD groups had significantly higher levels of alcohol knowledge than the ID group ($z = -3.560$; $p=0.001$ and $z=-2.739$; $p=0.006$ respectively). There were no significant differences between the ND and PD groups ($z=-1.309$; $p=0.191$) and therefore the hypothesis that the PD group would have lower levels of alcohol knowledge owing to limited opportunities to engage in situations where alcohol is present was not confirmed. However, in the ND group, 9 participants (29%) achieved the maximum score, compared to 3 participants in the PD group and 1 in the ID group. There was a greater range of scores in the ID group, suggesting greater variance in knowledge levels for this group.

Overall, knowledge about the relative strengths of different alcoholic drinks and recommended drinking limits was good. However, 3, 11 and 6 participants from the ND, ID and PD groups respectively thought it was safer and healthier to 'binge drink' than to spread the amount of alcohol consumed throughout the week, or were not sure. Young people with intellectual disabilities were less likely to agree that alcohol was a drug (ND: 26, ID: 14, PD: 18) and were less well informed about age restrictions in relation to drinking alcohol, with 23 participants believing that you have to be 21 years of age to drink. The most commonly held misconception in relation to alcohol consumption, and

shared across the three groups, was that either having something to eat or drinking coffee would help someone to sober up; only 12 participants from the ND group, 5 from the ID group and six from the PD group understood that nothing can sober you up but time.

6.2.3.2 Beliefs about Health Outcomes

As shown in table 6.4. there was a trend for the PD group (median = 29) to more strongly endorse correct and reject incorrect health outcomes associated with alcohol use than either the ND or ID groups (median = 28 and 27 respectively). For example, of all the responses given by participants in the PD group, 76% were coded as *very likely* for correct health outcomes and *not at all likely* for the incorrect health outcomes, whereas this was slightly less for the ND and ID groups (65 and 60% respectively). An explanation for this unexpected finding is discussed in section 7.7.

The relationship between alcohol consumption and vomiting, loss of coordination and the long term effects on the liver and memory were generally well understood across groups, although fewer participants in the ID groups endorsed these effects. This lower level of understanding may be due to participants with ID having fewer opportunities to experiment with alcohol or engage in social activities where alcohol is available. As might be expected, less well understood was the ability of alcohol to cause mouth disease; only 15, 11 and 10 participants from the ND, ID and PD groups respectively, stated that heavy long term alcohol use was *quite likely* or *very likely* to cause mouth disease. Several participants also believed that binge drinking would increase one's energy levels, this being endorsed by 3, 10 and 5 participants in the ND, ID and PD groups respectively. Four participants from the ID group stated that consuming alcohol would improve one's ability to drive.

6.2.4 Pregnancy and Contraception Knowledge

6.2.4.1 Multiple Choice Questions

Consistent with predictions, there were more marked differences in knowledge about pregnancy and contraception across groups, as shown in table 6.3. The ND group had the highest levels of knowledge (median = 9), followed by the PD group (median = 7) and the ID group (median = 6, $\chi^2 = 33.625$; $p=0.001$). This time the ND group scored significantly

higher than both the ID group (-5.344 ; $p=0.001$) and the PD group ($z=-4.242$; $p=0.001$). There were no differences between the PD group's pregnancy/contraception knowledge and that of the ID group's ($z=1.674$; $p=0.094$). A larger number of participants in the ND group achieved a maximum score (16, 51.6%), compared to the ID and PD groups (1 and 2 participants respectively). For the ID and PD groups, there was a much wider range of scores, suggesting greater variance in knowledge levels within these groups.

A misconception held by several participants in the ID group was the belief that in order for someone to become pregnant, sexual intercourse had to occur more than once, this being endorsed by 10 participants in the ID group. Three participants in the PD group but none of the ND group shared this belief. Across the groups, but particularly in the two disability groups, there was confusion over the role of the male orgasm in relation to pregnancy; 9 participants in the ND group, 19 in the ID group and 15 in the PD group believed a man had to have an orgasm to get a female pregnant or were unsure about this.

There were also misconceptions about the role of contraceptives in pregnancy and STI prevention, with 5, 8 and 2 participants in the ND, ID and PD groups respectively, believing that the contraceptive pill prevented HIV as well as pregnancy (5 of the ID group and 1 in the PD group were unsure). With regards to the condom, although the majority of the ND group knew that the condom could prevent both HIV and pregnancy, 2 participants were not aware condoms could prevent HIV. A few participants in the ID and PD groups also believed the condom *only* helped to prevent pregnancy (ID: 5, PD: 4) or that the condom only helped to prevent HIV (ID: 6, PD: 2) or were unsure (ID: 1, PD: 1). Five participants from the ID group and four from the PD group were unsure whether a new condom should be used at each sexual intercourse act. Participants in the ID and PD groups were less well informed about obtaining contraceptives than the ND group, with more participants believing you have to be aged 16 years or over to obtain the contraceptive pill (ND: 1, ID: 7, PD: 1) or the condom (ND: 1, ID: 7, PD: 8). Although the majority of all participants knew that the contraceptive pill could be obtained without charge, significantly more participants in the PD group were unaware that condoms could be obtained without cost (ND: 2, ID: 3, PD: 12).

6.2.4.2 Beliefs about Health Outcomes

Table 6.4. illustrates that, as with the multiple-choice questions, the ND group (median = 26) more strongly endorsed the true risk factors for pregnancy and rejected false risk factors than the ID group (median = 22) and the PD group (median = 24), although there were fewer differences between the ID and PD groups.

Participants were generally well informed about the improbability of falling pregnant when using a condom, using the contraceptive pill or though deep kissing. However, 4 participants in the ID group thought pregnancy was *quite likely* if a condom was used during sexual intercourse, and a further three thought pregnancy was *quite likely* if the female was on the contraceptive pill and one stated this was *very likely*. Four participants in the PD group also thought pregnancy was *quite likely* if the female was on the contraceptive pill. There was some confusion, particularly in the ID and PD groups, over whether a female could become pregnant whilst using the contraceptive injection, with several participants being unsure (ND: 2, ID: 8, PD: 7), and a few believing this was *quite likely* (ND: 3, PD: 2). When the distribution of responses was examined, an interesting trend emerged. A greater proportion of participants in the ND group than the other two groups stated that there was a small risk (i.e. it was a *bit likely*) a female could become pregnant when using a condom during sexual intercourse (ND: 15, ID: 5, PD: 7), or if the female was using the contraceptive pill (ND: 15, ID: 6 PD: 5) or the contraceptive injection (ND: 12, ID: 4 PD: 4; see appendix D). Participants in the ND group qualified their responses by commenting on the reliability of contraception, for example saying ‘*condoms don’t always work*’, ‘*they may burst*’, ‘*you may forget to take it (the pill)*’, or discussed how other factors affected the effectiveness of contraception, ‘*if you’re sick, the pill’s not as effective*’. Very few participants in the ID or PD groups mentioned such factors.

Participants across groups held many myths and misconceptions about pregnancy. For example, a number of participants in each group believed a female could not become pregnant if she was menstruating (ND: 10, ID: 16, PD, 12). Several participants also believed that a female was only *a bit likely* to become pregnant the first time sex occurs (ND: 6, ID: 9, PD, 8) or that it was *not at all likely* (ND: 4, ID: 10, PD, 6). Another misconception more commonly held by the ID group, but also by several participants in the PD group, was that having sexual intercourse whilst standing would make conception *not at all likely* (ND: 0, ID: 6, PD: 3) or only *a bit likely* to happen (ND: 4, ID: 7, PD: 5)

and washing oneself after intercourse would make conception *not at all likely* (ND: 0, ID: 2: PD: 5) or only *a bit likely* (ND: 4, ID: 2: PD: 2).

With regard to gender differences in responses, female participants in the ND group more strongly endorsed the belief that you can get pregnant the first time you have sexual intercourse than their male counterparts (14 females said this was *quite likely* or *very likely*, compared to 6 males) and that a female could get pregnant if she had sexual intercourse whilst she was menstruating (10 females said this was *quite likely* or *very likely*, compared to 3 males).

When presented with myths about pregnancy, a much larger proportion of the ND participants' responses fell into the *quite likely* to occur response category (ND: 49, versus ID: 18 and PD: 23%). These participants, although they acknowledged that pregnancy could occur for example when a female was menstruating or during first sexual intercourse, they also discussed how other factors determined whether pregnancy occurred or not, such as whether the female is ovulating or not. Therefore, despite giving more endorsement to the pregnancy myths, they were in fact demonstrating an awareness of the complexity of conception/pregnancy. For the two disability groups, responses were much more varied across categories and the factors influencing pregnancy discussed by the ND group were not discussed by participants in the two disability groups.

6.2.5 HIV and AIDS Knowledge

6.2.5.1 Multiple Choice Questions

As shown in table 6.3. young people from the ND and PD groups demonstrated the highest levels of knowledge in relation to HIV (medians = 7). The intellectual disability group scored the lowest (median = 5: $\chi^2 = 37.876$; $p=0.001$). Pairwise comparisons showed that the ND group were more knowledgeable than the ID group ($z=-5.919$; $p=0.001$) but not the PD group ($z=-1.824$; $p=0.068$). In turn, the PD were more knowledgeable than the ID group ($z=-4.146$; $p=0.001$). A larger number of participants in the ND and PD groups achieved a maximum score (ND: 10, 32.3% and PD: 5, 21.7%), compared to none of the ID group. For the ID group, there was a much wider range of scores, suggesting greater variance in knowledge levels for this group. Therefore, the hypothesis that both the ID and PD groups would have greater knowledge gaps than the non-disabled peers was not fully

supported, although the ND group demonstrated a trend toward greater HIV knowledge. This is discussed further in section 7.7.

Overall, females in the ND group were more knowledgeable about AIDS than males although there was not one item that clearly distinguished the males and females. In addition, males in the ID group also outperformed their female counterparts and these differences are discussed below.

There were many misconceptions across the three groups in relation to HIV and AIDS, although as predicted these were more commonly endorsed by the two disability groups. These misconceptions included the belief that an individual infected with HIV can always be cured (ND: 8, ID: 12, PD: 17) or that there is a HIV vaccine available (ND: 2, ID: 11, PD: 6). As expected, the idea that an infected individual is more susceptible to other infections was poorly understood by the ID group; 9 participants in the ID group answered this question incorrectly, compared to 2 and 4 participants from the ND and PD groups respectively. In relation to this, participants in the ID group were more likely to state that HIV status can be determined from someone's appearance (ND: 2, ID: 10, PD: 4). A few participants in the two disability groups also believed that lifestyle factors influenced one's likelihood of contracting HIV, for example poor levels of hygiene (ID: 5, PD: 3) and poor eating/exercising habits (ND: 1, ID: 5, PD: 3). Four individuals in the ID group also believed that it was only males or homosexuals that could contract HIV, all of whom were females.

6.2.5.2 Beliefs about Health Outcomes

Table 6.4. shows that overall the ND group gave stronger endorsement to true risk factors and were more likely to reject false risk factors for HIV transmission (median = 28) than the PD group (median = 27), who in turn scored higher than the ID group (median = 24).

With regard to the true risk factors for HIV transmission, all participants understood the risk of sharing needles and having unprotected sex. Although the majority of the ND group (29 participants) thought it was *quite likely* or *very likely* a mother could pass on the HIV virus to her baby, participants in the ID and PD groups were less sure, with 14 and 16 participants respectively stating this was *quite likely* or *very likely*. A number of participants believed that the risk of HIV being transmitted via touching an infected

person's cut was *not at all* or *a bit likely* (ND: 16, ID, 12, PD: 7). However, when prompted, the majority of participants in the ND group and 3 of the PD group justified their response by stating that both the infected person and the 'victim' would need to have an open wound for HIV to be transmitted, and this information could not be deduced from the question. When participants from the ID group were provided with this additional information, they still perceived it as low risk behaviour.

The risk of transmitting HIV through kissing was less well understood by the ID group, with 16 participants perceiving this to be a risky behaviour, as did 7 participants in the PD group and only 2 in the ND group. Four participants in the ID group also believed that hugging an infected person could lead to HIV infection (as did 1 in the PD and ND group) and 6 thought sharing a swimming pool with an infected person was dangerous. There was some confusion across groups as whether an insect bite could transmit HIV, with 10 participants in the ND group, 8 participants in the ID and PD group believing this was *quite likely* or *very likely* or were unsure.

6.3 Social Networks

In this section, differences in participants' social networks are explored. The main data extracted from the semi-structured interviews were participants' i) number of friendships within school or college, ii) number of friendships continued outside of, and/or external to, school or college, iii) number of activities engaged in per week with peers and iv) number of activities engaged in per week with family members. Data was not normally distributed nor were the variance of the populations equal, therefore a Kruskal-Wallis one-way analysis of variance was used to explore differences in social network data across groups. The summary scores for the three groups are displayed in table 6.5

6.3.1 Close Friendships Within and Outside of School/College

The participants in the ID and PD group had impoverished social networks when compared to the ND group. They reporting have both fewer close friendships within their school/college (medians: ND: 8, ID: 4, PD: 5, $\chi^2=12.894$; $p=0.002$) and fewer friendships that continued outside of, and/or external to, school/college (medians: ND: 7, ID: 3, PD: 3, $\chi^2=26.894$; $p=0.001$). Pairwise comparisons revealed that the ND group reported having more friends both within and outside of school/college than the ID group ($z=-3.406$ and $z=-5.054$; $p=0.001$ respectively) and the PD group ($z=-2.520$; $p=0.02$ and $z=-3.622$; $p=0.001$ respectively). There were no differences between the two disability groups ($z=-0.681$; $p=0.5$ and $z=-0.056$; $p=1.0$ respectively). Whereas 15 out of the 34 participants in the ND group said they had a boyfriend or girlfriend, this compared to only two participants in the ID or PD groups.

6.3.2 Frequency of Time Spent with Friends and with Family

Data was gathered on the number of activities engaged in per week in an activity with friend(s) outside of school/college and with other family members. There were significant differences across the three groups in terms of time spent with friends ($\chi^2=35.924$; $p=0.001$), with participants in the ND group reporting engaging in a higher number of activities with their peers each week (median = 4) than either the ID or PD group (medians = 2; $z=-5.045$ and $z=-5.081$; $p=0.001$ respectively). There were no differences between the

ID and PD groups ($z=-0.842$; $p=0.4$). With regards to time spent with family, overall there were no differences between the groups ($\chi^2=6.090$; $p=0.5$).

Table 6.5 Summary Scores for Social Network Data

	No-Disability <i>n</i> 31	Intellectual Disability <i>n</i> 29	Physically Disability <i>n</i> 23
Friends Within School/college			
Mean	9.7 ^a	5.5 ^b	6.7 ^b
Median	8	4	5
Range	3-26	2-12	1-25
SD	5.6	2.75	5.4
Friends Outside School/college			
Mean	8.7 ^a	3.5 ^b	4.48 ^b
Median	7	3	3
Range	2-26	0-8	0-20
SD	5.1	1.9	4.7
Time Spent with Peers			
Mean	4.7 ^a	2 ^b	1.7 ^b
Median	4	2	2
Range	1-9	0-4	0-5
SD	1.9	1.3	1.3
Time Spent with Family			
Mean	1.4 ^a	2 ^a	1.7 ^a
Median	1	2	1
Range	0-7	0-4	0-3
SD	1.4	1.0	0.9

Means that do not share a superscript in common are significantly different from each other.

6.4. Sources of Health Information

In this section the types of sources young people reported having accessed for information about the different health topics are explored. As data were categorical, the Kruskal-Wallis One Way Analysis of Variance for independent groups was used to explore differences across groups. Where significant effects were found, pairwise comparisons were then performed using the Mann-Whitney test to identify where these differences lay. The summary scores for the three groups are displayed in table 6.6.

The ND group were more likely to report having spoken to friends about healthy eating, alcohol or pregnancy/contraception than either the ID group (healthy eating: $z=-2.068$; $p=0.04$, alcohol: $z=-2.471$; $p=0.01$, and pregnancy/contraception: $z=-4.933$; $p=0.001$) or the PD group (healthy eating: $z=-3.124$; $p=0.02$, alcohol: $z=-2.550$; $p=0.01$ and pregnancy/contraception: $z=-3.381$; $p=0.001$). The ND group were more likely to report

having spoken family members or health professionals about pregnancy/contraception than the ID group (family: $z=-3.357$; $p=0.001$ and health professional: $z=-3.151$; $p=0.002$) or the PD group (family: $z=-3.387$; $p=0.001$ and health professional: $z=-3.314$; $p=0.002$). Differences between the ID and PD groups were minimal.

Young people from the PD group were more likely to have learnt about alcohol and HIV from school than the ND group (alcohol: $z=-2.804$; $p=0.05$ and HIV: $z=-3.710$; $p=0.001$) or the ID group (alcohol: $z=-2.154$; $p=0.03$ and HIV: $z=-2.607$; $p=0.01$).

Table 6.6: Summary Scores for Sources of Information Data

	No-Disability		Intellectual Disability*		Physically Disability	
	31	%	29	%	23	%
Friends						
Healthy Eating	24^a	77.4	15^b	51.7	8^b	34.8
Alcohol	28^a	90.3	18^b	62.1	14^b	60.9
Contraception/pregnancy	27^a	87.1	6^b	20.7	10^b	43.5
HIV	8	25.8	4	13.8	3	13.0
Family						
Healthy Eating	27	87.1	21	72.4	14	60.9
Alcohol	22	71.0	17	58.6	14	60.9
Contraception/pregnancy	25^a	80.6	11^b	37.9	8^b	34.8
HIV	6	19.4	8	27.6	3	13.0
School						
Healthy Eating	26	83.9	26	89.7	23	100
Alcohol	22^a	71.0	24^a	82.8	23^b	100
Contraception/pregnancy	23	74.2	26	89.7	22	95.7
HIV	17^a	54.8	21^a	77.8	23^b	100
Health Professional						
Healthy Eating	12	38.7	11	37.9	7	30.4
Alcohol	10	32.3	13	44.8	5	21.7
Contraception/pregnancy	21^a	67.7	8^b	27.6	5^b	21.7
HIV	8^a	25.8	10^a	37.0	1	4.3
Media						
Healthy Eating	27	87.1	27	93.1	23	100
Alcohol	20	64.5	20	69.0	20	87.0
Contraception/pregnancy	16	51.6	15	51.7	15	65.2
HIV	26^a	83.9	14^b	51.9	14^{ab}	60.9

Means that do not share a superscript in common are significantly different from each other. *In the ID group, 28 participants completed the contraception/pregnancy questionnaire and 27 completed the HIV/AIDS questionnaire

Participants in the ND and ID groups were more likely to report having received information from a health professional about HIV than the PD group ($z=-2.073$; $p=0.04$ and $z=-2.528$; $p=0.01$ respectively), although these were very small numbers. The ND group also reported having learnt about HIV from the media more than the ID group ($z=-2.866$; $p=0.004$).

6.5 Associations between Health Knowledge, Social Networks and Sources of Information

The above analyses demonstrated that there were distinct differences across the three groups in terms of health knowledge, social networks and sources accessed for health information. Therefore, the next step was to explore how these different variables interacted to influence young people's health knowledge. One possible approach would be to use multivariate statistical techniques, such as a regression analysis. This would involve collapsing the data across the three groups for each health questionnaire (healthy eating, alcohol, pregnancy/contraception and HIV/AIDS) and exploring the relationship between one or more explanatory or independent variables (i.e. sources of information and social networks) and a single continuous dependent variable (health knowledge scores). One of the main advantages of regression analysis is that it can control for other independent variables, such as IQ scores, age and gender, and is less subject to the problems of multiple testing. Consequently, it is recognised that this would be a potentially useful approach and should be considered in future research.

However, the current study was exploratory and to conduct a regression analyses would have required a larger sample size. Therefore, it was decided to adopt a more conservative approach to analysing the data. The initial stage in analysing the associations between health knowledge, social networks and sources of information involved using exploratory data analysis (EDA; Turkey, 1980). This exploratory approach served to generate hypotheses worthy of further consideration, and highlighted interesting and unexpected insights from the data.

This is particularly useful approach when an a priori model is not available, or is difficult to construct. Even though hypotheses about the associations between health knowledge and social exclusion were generated (discussed in the previous section), there is limited prior theoretical and empirical research examining these associations. It was anticipated that through identifying the most relevant variables, confirmatory data analysis techniques could then be employed to evaluate associations among the various factors in future research, for instance using regression analysis or non-parametric logistic-regression models.

Initial data analyses involved exploring bivariate associations between variables using the Spearman's rank correlation coefficient for non-parametric data. Analyses were conducted separately for each health topic (healthy eating, alcohol, pregnancy/contraception and HIV/AIDS) and each group (ND, ID and PD). The main associations of interest were as follows:

Health Knowledge and Social Network: Are participants who report having more friends in their social network more knowledgeable about health? Are participants who spend more time socialising with their peers more knowledgeable about health matters? Are participants who report spending more time socialising with family members more knowledgeable about health?

Social Network and Accessing 'Friends' for Health Information: Are participants with larger social networks more likely to report speaking to their friends about health matters? Are participants who spend more time socialising with their peers more likely to discuss health matters with their friends?

Health Knowledge and Sources of Information Accessed: Are participants who access more sources for health information more knowledgeable about health? Is discussing health matters with friends associated with being more knowledgeable about health?

In addition, the association between these variables and **age** and **IQ** scores were explored.

The correlation matrix for coefficients is shown in table 6.7, 6.8 and 6.9., with significant correlations highlighted in bold. It is acknowledged that running multiple correlations increases the chances of finding a significant result by chance. Although it may be prudent to use a more stringent alpha level of 0.001 when examining the associations between variables, as these analyses are exploratory, any potentially interesting or informative trends are discussed and results should be treated as suggestive rather than conclusive. Despite there being marked between group differences across these variables, there were few consistent or strong associations. However, several trends emerged that warranted further exploration and these are discussed in the remainder of this section.

It should also be noted that some of the variables were interrelated. For example, the number of sources accessed for a given health topic frequently correlated with whether participants reported having spoken to a friend about that topic or not. This was due to 'friend' being one of responses that made up the 'number of sources accessed' variable. Consequently, despite these values being significantly associated, they are not discussed here.

Age

Few variables examined in table 6.7. were associated with age. Healthy eating knowledge increased with age in the ND group ($r_s=0.36$; $p=0.03$) and there was a positive association between having ever spoken to a friend about healthy eating and age in the ID group ($r_s=0.58$; $p=0.01$). However, in the PD group, both healthy eating knowledge and having spoken to a friend about HIV were *negatively* correlated with age (Healthy eating: $r_s=0.32$; $p=0.05$, HIV: $r_s=0.41$; $p=0.03$).

As age was not associated with sexual health knowledge, this strengthens the findings of the previous sections as it suggests that the differences that were observed across the three groups were not a result of differences in participants' age.

IQ Scores

With regard to associations between IQ scores and health knowledge, there were a number of positive associations for the ND and PD groups. Interestingly, associations between IQ and sexual health knowledge were only apparent for the ND group, which would support the earlier reported finding that cognitive ability is not the only factor in determining knowledge about sexual matters in people with disabilities. In other words, it did not seem likely that the PD group were performing poorly on the sexual health questionnaire because of lower cognitive ability. For the ID group, IQ scores positively correlated with number of friendships reported external to school/college. This supports previous research that found individual characteristics such as adaptive skills are important factors in determining friendship and social networks for people with intellectual disabilities (Emerson and McVilly, 2004). Interestingly, participants in the ND group with lower IQ scores were more likely to report spending time with their family. Finally, an unexpected finding was the negative association between IQ scores and number of sources accessed

for HIV information by the ID group, suggesting as IQ scores increase, the number of sources accessed decrease. It is acknowledged that in calculating a large number of correlation coefficients the risk of a type I error occurring is high; in other words, the associations observed could have occurred by chance. Consequently, extreme caution should be taken when trying to interpret these results.

Healthy Eating Knowledge

There were some trends suggesting an association between friends and social networks and healthy eating knowledge. For the ND group, healthy eating knowledge was associated with the number of friendships outside of school/college ($r_s=0.31$; $p=0.04$) and there was a trend for such knowledge to be associated with ever having spoken to a friend about healthy eating ($r_s=0.22$; $p=0.1$). Participants in the PD who reported speaking to friends about healthy eating were also more knowledgeable ($r_s=0.43$; $p=0.02$).

Alcohol Knowledge

Trends were less clear with regard to alcohol knowledge. For the two disability groups, spending *more* time with friends was associated with lower levels of knowledge about alcohol (ID: $r_s=-0.43$; $p=0.01$, PD: $r_s=-0.46$; $p=0.01$). For the ND participants, spending less time with family members was associated with being more knowledgeable about alcohol ($r_s=-0.30$; $p=0.05$).

Pregnancy and Contraception Knowledge

For the ID and PD groups, there were some interesting trends observed across the variables. There were associations between participants in the ID groups' sexual knowledge and i) the number of sources accessed for sexual health information ($r_s=0.67$; $p=0.01$), ii) whether participants reported having spoken to a friend about sexual health ($r_s=0.41$; $p=0.02$) and iii) the number of friendships reported external to school/college ($r_s=0.33$; $p=0.05$). However, care should be taken when interpreting these findings, as IQ scores were also associated with number of friends outside of school/college ($r_s=0.50$; $p=0.01$) and this could in part be responsible for the strong associations between these variables. However, the finding that participants in the PD groups' sexual knowledge was also associated with number of friendships reported external to school/college ($r_s=0.47$;

$p=0.01$) would suggest that this is worthy of further investigation. Interestingly, in the ND group spending more times with friends was associated with lower levels of sexual knowledge ($r_s=-0.61$; $p=0.01$).

HIV / AIDS Knowledge

Associations between the different variables and HIV knowledge suggested that talking or socialising with friends was not related to higher levels of knowledge. For participants in the ND group, spending more time with friends was negatively associated with knowledge about HIV ($r_s=-0.40$; $p=0.01$), and for ID and PD groups there was a negative association between talking to friends about HIV and knowledge (ID: $r_s=-0.33$; $p=0.05$, PD: $r_s=-0.40$; $p=0.03$). However, for the ND group, there was an association between spending time with friends and having spoken to them about HIV ($r_s=0.31$; $p=0.05$), even if this was not associated with knowledge levels.

Summary

Exploratory data analysis was used to uncover patterns in the data. It was the intention to use confirmatory data analysis techniques to explore and validate the associations identified during this exploratory phase. Although several interesting trends have emerged, these were not strong or consistent enough to be able to fit the data to a model. In addition, it should be strongly emphasised that owing to the many correlations that have been carried out during this analysis, only very cautious statements can be made about associations between these variables. On the other hand, this is an advantage of using EDA; it allows the researcher to generate more specific research questions from the existing data and by identifying what is missing from the data, enables future research to be improved by informing study design and data collection.

The fact that there were associations between sexual health knowledge, sources of information and social network data for the ID and PD groups suggests that this is an area that should be explored further, particularly as the between-group analyses described sections 6.2. and 6.3. highlighted the importance of these. Increasing the sample size would enable the validity of these possible associations to be explored. In addition, a larger sample is needed to examine any gender differences across these variables, which may be masking true associations. However, whilst increasing sample size is important, the

exploratory analyses also revealed several inconsistencies across the data. This may reflect weaknesses in the scales used. For example, the social network measure only tapped into a very limited aspect of participants' social networks and future work would need to use more robust and in-depth measures if true relationships between the data are to be discovered.

Table 6.7: Spearman Rank-Order Correlation Coefficients and P Values – No Disability Group

		IQ Score	Age	Healthy Eating			Alcohol			Pregnancy/ Contraception			HIV / AIDS			Social Network			
				Knowledge	No. Sources	Spoken to 'Friend'	Knowledge	No. Sources	Spoken to 'Friend'	Knowledge	No. Sources	Spoken to 'Friend'	Knowledge	No. Sources	Spoken to 'Friend'	School Friends	External Friends	Friends - Frequency	Family - Frequency
Healthy Eating	IQ Score	1.00																	
	Age	0.35	1.00																
	Knowledge	0.17	0.29	1.00															
	No. Sources	0.15	0.07	0.31	1.00														
	Spoken to 'Friend'	0.11	0.24	0.22	0.60	1.00													
Alcohol	Knowledge	0.31	0.36				1.00												
	No. Sources	-0.16	0.01				-0.10	1.00											
	Spoken to 'Friend'	0.01	-0.14				-0.11	0.29	1.00										
Contraception	Knowledge	0.31	-0.03							1.00									
	No. Sources	0.07	0.09							0.03	1.00								
	Spoken to 'Friend'	0.38	0.12							0.07	0.58	1.00							
HIV / AIDS	Knowledge	0.12	0.20										1.00						
	No. Sources	0.15	-0.04										-0.24	1.00					
	Spoken to 'Friend'	0.15	0.20										-0.17	0.52	1.00				
Social Network	School Friends	0.19	-0.02	0.25	-0.18	-0.10	-0.10	-0.26	0.03	0.28	-0.19	0.11	0.16	0.22	-0.11	1.00			
	External Friends	0.10	0.02	0.38	-0.02	-0.06	-0.08	-0.09	-0.03	0.21	-0.18	0.07	0.15	0.29	-0.05	0.92	1.00		
	Friends - Frequency	-0.19	0.20	-0.07	0.13	-0.15	0.02	0.16	-0.25	-0.61	0.05	-0.30	-0.40	0.04	0.24	-0.12	-0.03	1.00	
	Family - Frequency	-0.38	-0.15	-0.09	-0.16	0.01	-0.304	-0.09	0.08	0.02	-0.10	-0.19	-0.13	-0.15	-0.31	-0.03	-0.13	-0.37	1.00

Values in bold are significant at the level of ≤ 0.05 ; values in bold and red are significant at the level of ≤ 0.01

Table 6.8: Spearman Rank-Order Correlation Coefficients and P Values - Intellectual Disability

				Healthy Eating			Alcohol			Pregnancy/ Contraception			HIV / AIDS			Social Network			
		IQ Score	Age	Knowledge	No. Sources	Spoken to 'Friend'	Knowledge	No. Sources	Spoken to 'Friend'	Knowledge	No. Sources	Spoken to 'Friend'	Knowledge	No. Sources	Spoken to 'Friend'	School Friends	External Friends	Friends - Frequency	Family - Frequency
Healthy Eating	IQ Score	1.00																	
	Age	-0.18	1.00																
	Knowledge	0.00	0.02	1.00															
	No. Sources	0.09	0.17	0.18	1.00														
	Spoken to 'Friend'	0.14	0.58	-0.13	0.53	1.00													
Alcohol	Knowledge	0.20	-0.29				1.00												
	No. Sources	0.10	-0.14				-0.03	1.00											
	Spoken to 'Friend'	0.19	-0.26				0.20	0.58	1.00										
Contraception	Knowledge	0.08	0.03							1.00									
	No. Sources	-0.26	0.12							0.67	1.00								
	Spoken to 'Friend'	-0.23	0.13							0.41	0.53	1.00							
HIV / AIDS	Knowledge	-0.03	0.03										1.00						
	No. Sources	-0.5	-0.02										-0.20	1.00					
	Spoken to 'Friend'	-0.18	0.03										-0.33	0.52	1.00				
Social Network	School Friends	-0.07	0.08	0.07	-0.10	-0.15	0.07	0.28	0.29	0.29	0.09	0.21	0.03	-0.20	-0.10	1.00			
	External Friends	0.5	-0.15	0.10	0.35	0.12	0.26	0.28	0.35	0.33	-0.04	0.01	0.12	-0.20	-0.25	0.25	1.00		
	Friends - Frequency	0.08	-0.12	-0.07	-0.17	-0.11	0.14	-0.35	0.04	0.12	0.11	0.28	-0.04	0.11	-0.01	-0.05	0.14	1.00	
	Family - Frequency	-0.17	-0.12	0.27	0.18	-0.04	-0.19	0.27	-0.03	-0.07	0.19	0.03	-0.14	0.03	-0.10	-0.22	-0.17	-0.48	1.00

Values in bold are significant at the level of ≤ 0.05 ; values in bold and red are significant at the level of ≤ 0.01

Table 6.9: Spearman Rank-Order Correlation Coefficients and P Values - Physical Disability Group

				Healthy Eating			Alcohol			Pregnancy/ Contraception			HIV / AIDS			Social Network			
		IQ Score	Age	Knowledge	No. Sources	Spoken to 'Friend'	Knowledge	No. Sources	Spoken to 'Friend'	Knowledge	No. Sources	Spoken to 'Friend'	Knowledge	No. Sources	Spoken to 'Friend'	School Friends	External Friends	Friends - Frequency	Family - Frequency
Healthy Eating	IQ Score	1.00																	
	Age	0.20	1.00																
	Knowledge	0.20	-0.32	1.00															
	No. Sources	0.19	0.09	0.23	1.00														
	Spoken to 'Friend'	0.19	0.13	0.43	0.60	1.00													
Alcohol	Knowledge	0.38	-0.02				1.00												
	No. Sources	0.34	-0.11				0.19	1.00											
	Spoken to 'Friend'	0.03	-0.03				0.01	0.74	1.00										
Contraception	Knowledge	0.24	0.21							1.00									
	No. Sources	0.33	0.01							-0.14	1.00								
	Spoken to 'Friend'	0.21	0.21							0.10	0.59	1.00							
HIV / AIDS	Knowledge	-0.21	-0.10										1.00						
	No. Sources	0.12	-0.06										-0.23	1.00					
	Spoken to 'Friend'	0.01	-0.41										-0.40	0.64	1.00				
Social Network	School Friends	-0.04	-0.13	0.05	-0.18	-0.28	-0.09	-0.05	-0.10	0.31	-0.01	-0.08	0.12	-0.16	-0.06	1.00			
	External Friends	-0.07	0.11	0.27	-0.16	-0.15	-0.15	-0.19	0.01	0.47	-0.16	-0.10	-0.01	-0.14	-0.13	0.54	1.00		
	Friends - Frequency	0.04	-0.10	0.33	-0.20	-0.19	-0.46	0.01	0.23	0.30	0.08	0.05	0.12	0.04	0.06	0.5	0.58	1.00	
	Family - Frequency	0.28	0.07	0.21	0.36	0.07	-0.17	0.20	0.03	0.01	0.32	0.28	-0.22	0.42	0.30	-0.13	-0.03	-0.10	1.00

Values in bold are significant at the level of ≤ 0.05 ; values in bold and red are significant at the level of ≤ 0.01

6.6 Summary: Phase I Quantitative Data

Consistent with the previous, albeit limited, research that has compared the health knowledge in individuals with intellectual and physical disabilities with their non-disabled peers, the current study found that young people with intellectual disabilities had least understanding of health matters (Duh, 2000; McCabe, 1999; McCusker et al., 1993; Szollos and McCabe, 1995). Young people without disabilities in the current study demonstrated higher levels of knowledge than the physical disability group, who in turn demonstrated higher levels of knowledge than the intellectual disability group.

6.6.1 Health Topics in the Public Domain

The smallest differences between groups in terms of knowledge were reported with health matters more in the public domain, such as healthy eating and alcohol. The main differences between groups were that participants in the ID group were more likely to believe that *'eating only salad is very good for you'* than participants in the ND and PD groups, and were less certain about the health outcomes associated with a healthy and unhealthy diet. With regard to alcohol, participants in the ID group were less likely to agree that alcohol was a drug and more likely to state that the minimum age for the purchase of alcohol is 21. Across groups, participants held myths about alcohol such as coffee and eating can sober up a drunk person, although this was more common amongst the two disability groups.

6.6.2 Health Topics in the Private Domain

The largest differences between the groups were related to health issues considered to be more personal and private, such as pregnancy and contraception, with both groups of young people with disabilities having lower levels of sexual health knowledge than their non-disabled peers. Thus, deficits in sexual knowledge were not just a result of the ID group's cognitive deficits which were seen with the healthy eating and alcohol scales.

It was predicted that knowledge about HIV would be lower than for other health areas, as it is a complex topic to understand and a private matter surrounded by taboos and myths. Both the ND and PD group were more knowledgeable about HIV than the ID group suggesting that cognitive ability was important. Although there were no significant

differences between the ND and PD groups, the ND group demonstrated a trend toward greater HIV knowledge. However, across the three groups information about HIV was infrequently accessed, perhaps owing to participants not perceiving themselves to be vulnerable to HIV infection (Abraham, Sheeran and Johnston, 1991).

6.6.3 Sources of Information

In contrast to healthy eating and alcohol, sexual health is a more private and sensitive topic. Consequently, it is important to have a variety of formal and informal sources to which individuals can turn to for information, including family, friends, the media, health professionals and formal sex education. However, young people with disabilities reported having fewer sources of support than their non-disabled peers, particularly in relation to sexual health topics. One of the most striking findings was that young people with disabilities said they were less likely to talk to their friends about healthy eating, alcohol, and pregnancy/contraception, and were less likely to report speaking to a family member or health professional about pregnancy/contraception than their non-disabled peers. In turn, there were few differences between the sources used by young people with intellectual or physical disabilities.

Despite the young people with disabilities reporting having limited information sources for matters around sex, this actually compared favourably with previous studies. For example, McCabe (1999) reported that 5% of participants with ID, 27% of participants with PD had obtained information about sexuality from their friends, compared to 71% in a sample from the general population. The corresponding figures in the current study were 21%, 44% and 87%, respectively. Confounding factors, such as level of disability, gender and age may influence the extent discussions about sexuality take place or what information is accessed. Hence, comparisons across studies are difficult, particularly when such factors not always taken into consideration when analysing data.

6.6.4 Social Networks

Young people also gain information about sex through observing and interacting with their peers and other people, as well as through experience. Yet participants in both the ID and PD groups had impoverished social networks and this could have reduced their opportunities for experiential learning about sexual matters (Cole and Cole, 1993).

Exploratory data analyses also revealed a possible association between sexual health knowledge and the number of sources of information available to participants, and pointed to the potential role of friends in developing sexual knowledge. Although these findings have to be interpreted very cautiously, they warrant further exploration.

6.6.5 Gender and Age Differences

Attitudes to information and knowledge may also vary significantly with gender (Abraham et al., 1991; Measor, 2004; Oh et al., 2005; Wellings et al., 2001). For example females report a greater reliance on families, in particular mothers, for support whereas males rely more on peers and media, such as pornography (Measor, 2004). However, gender differences in participants' responses were not explored in the current study and this may have masked significant differences between the groups.

It is also important to note that the PD group was younger than the ND or ID groups. Although associations between age and health knowledge were not apparent, this may have been a result of the smaller variance in age seen with the PD group. Age is of particular importance when considering health behaviours that are age restricted, for example consuming alcohol and engaging in sexual intercourse. As the opportunities to engage in these activities increase with age, one may expect knowledge to also accumulate.

Chapter 7: Phase I Qualitative Data: Health Understanding

7.1 Introduction

The aims and objectives of the study were outlined in chapter 5 and this chapter will focus on the semi-structured interviews. As far as it was possible, individuals who had completed the structured questionnaires also took part in the semi-structured interviews. This allowed comparisons to be made across the two types of data (quantitative and semi-structured interviews) and helped provide a deeper insight into the participants' health understanding. Interviewing the same participants was considered important as this allowed the rapport that had already been established with the participants to be capitalised upon. This facilitated a more in-depth exploration of the health topics, as the participants felt more confident and comfortable in answering questions. This section will provide descriptive information about the participants who completed the health interviews and will explore their health understandings.

7.2 Participants' Demographic Characteristics

Eighty-three participants completed the structured questionnaires, of which 31 had no known disability (ND), 29 had an intellectual disability (ID) and 23 had a physical disability (PD). The IQ scores, ages and numbers of participants who also completed the semi-structured interviews are displayed in table 7.1 and figure 5.2 shows a flow chart for the recruitment of study participants. There were no differences between participants who did and did not go on to complete the semi-structured interviews, and as such only means are presented here. The number of participants in each group who completed both the structured and the semi-structured health interviews is shown in table 7.1. The reason for participants not taking part in the semi-structured interviews was unavailability at follow-up, either because participants had moved course/college or they declined to take part any further owing to other college commitments (such as coursework or examinations). In addition three participants in the ID group demonstrated no knowledge of HIV or AIDS, and although the interview was initiated, it had to be terminated early on and therefore data are not presented for these individuals.

Table 7.1: Participants' Demographic Characteristics*

	No Disability	Intellectual Disability	Physically Disability
<i>Completed Quantitative Interview</i>	<i>n31</i>	<i>n29</i>	<i>n23</i>
Healthy Eating	<i>n 29</i>	<i>n 29</i>	<i>n 23</i>
IQ score	97.2	59.6	92.7 (95.7†)
Age	18.9	18.6	16.7
Alcohol	<i>n 28</i>	<i>n 24</i>	
IQ score	97.2	59.2	as above
Age	19	18.7	
Pregnancy/contraception	<i>n 23</i>	<i>n 22</i>	
IQ score	96.6	58.9	as above
Age	18.9	18.6	
HIV	<i>n 24</i>	<i>n 20</i>	
IQ score	96.8	58.3	as above
Age	18.8	18.7	

* Data relating to participants demographic characteristics has been presented in chapter 7, as such only means are presented here. † These scores have been adjusted by two standard errors of measurement.

The semi-structured questionnaire consisted of two main parts. Section 1 consisted of open ended questions exploring participants' spontaneous beliefs about healthy eating, alcohol consumption, pregnancy/contraception and HIV/AIDS. Section 2 used a card sorting task to explore participants' understandings of these health topics (as discussed in section 5.10.3) Data analysis and interpretation is discussed in detail in section 5.10.5., but an overview is also given here. In section 1, content analysis was used to explore participants' responses to the open ended questions. Transcripts were read carefully for overall content and identification of major themes (Hickey and Kipping, 1996; Hsieh and Shannon, 2005; Weber, 1994). Frequency counts were then made and compared across the three groups. In section 2, content analysis was used to explore participants' understandings about the four health topics. Based on the transcripts and existing coding schemes (e.g. Perrin and Gerrity, 1981), a hierarchical coding system was developed that explored the sophistication of participants' understandings. The majority of the responses could be coded into one of these major categories and again comparisons were made across the three groups.

7.3 Healthy Eating Knowledge

7.3.1 Section 1: *Spontaneous Beliefs about a Healthy and Unhealthy Diet*

Participants' salient beliefs about what constitutes a healthy and an unhealthy diet, and their understanding of why it is important to include some foods but not others, were examined through their responses to the open-ended questions. It was important to allow participants to use their own classification system when grouping foods, for example discussing specific food items (such as meat, chips) or naming a food group (i.e. protein, fat), as the aim was to make the interview relevant to participants' everyday food choices. Overall, participants in the ID group were the least knowledgeable about healthy eating, and their explanations regarding the role of food in health and illness tended to be less sophisticated, even with the use of visual and verbal prompts. Participants in the ND and PD groups demonstrated similar levels of understanding about healthy eating.

7.3.1.1 Listing of 'Healthy Foods'

As shown in table 7.2., in response to the question *'If someone was trying to eat healthily, what foods should they try to eat?'* overwhelmingly participants mentioned the importance of including fruit and vegetables; only one participant in the ID group failed to mention this. The majority of participants were also able to cite the recommended target of consuming 'five-a-day' of fruit and vegetables. Other foods considered healthy were carbohydrate-rich foods, exemplified through items such as bread, cereals and pasta. Several participants from the ND and PD groups were able to distinguish between starchy (complex) carbohydrates and simple sugars. These participants discussed how starchy carbohydrates found in bread, pasta and cereals are particularly good for sustained energy, whereas simple sugars found in chocolate, sweets and fizzy drinks only give short-term energy. Foods high in protein such as fish, meat, nuts and pulses, dairy products such as milk, cheese and eggs and drinking plenty of fluids were included in descriptions of healthy diets. Several participants from the ND and PD groups (none in the ID group) recognised that there are different types of fats, with unsaturated fats such as olive oil and fish being essential for a healthy diet and saturated animal fats being unhealthy.

Table 7.2: Perception of Healthy Foods and their Associated Health Benefits

	No Disability <i>n</i> 29	Intellectual Disability <i>n</i> 29	Physically Disability <i>n</i> 23
Healthy Foods			
Fruit and vegetables	29	28	23
'Five-a-day'	22	17	17
Carbohydrate-rich foods	15	12	22
Starchy vs. simple sugars	7	0	7
Protein	22	9	15
Dairy products	8	7	6
Essential fats	7	0	6
Water	8	4	5
Health benefits			
Growth, repair & strength	26	6	19
Source of energy	25	5	11
Role of vitamins	16	4	13
Weight maintenance	12	7	12
Skin, hair & nails	11	5	12
Digestive system	8	5	5
Circulation	6	0	5
Heart	4	2	2
Teeth	3	2	1

7.3.1.2 Health Benefits Related to Healthy Eating

The most commonly described benefits of consuming these 'healthy' foods are displayed in table 7.2 and included is their role in the body for growth, repair and strength, as well as being a good source of energy. Eating these foods was associated with maintaining or reducing weight, mainly explained through their low fat and sugar content. Participants also discussed how consuming a healthy diet could be beneficial for the digestive system (through the fibre content), circulation (through iron found in protein; ND and PD groups only), the heart, teeth and skin, hair and nails. Several participants from each group discussed vitamins found in these foods, although only the ND and PD groups could elaborate on their function, for example in maintaining healthy blood/circulation, the immune system, and skin, hair and nails.

7.3.1.3 Listing of ‘Unhealthy Foods’

Across all groups participants were able to offer more foods that they considered being unhealthy than healthy options. As shown in table 7.3. items discussed here consisted mainly of foods with a high fat and/or sugar content, such as fried foods (chips, fried fish/chicken, doughnuts), fast foods (take-away, e.g. burgers, chips, curries, ‘McDonalds’), biscuits, cakes and desserts, confectionary (sweets, chocolates, ice-cream) and soft drinks (carbonated and still drinks, e.g. ‘Irn-Bru’, cola, cordial). Fewer participants discussed foods high in salt and even fewer could identify foods that were high in salt.

Table 7.3: Perception of Unhealthy Foods and their Associated Health Consequences

	No Disability <i>n</i> 29	Intellectual Disability <i>n</i> 29	Physically Disability <i>n</i> 23
Unhealthy Foods			
Fried foods	24	25	20
Fast/processed foods	22	21	21
Biscuits, cakes & desserts	24	18	18
Confectionery	26	25	21
Soft drinks	19	12	16
Salt	7	3	4
Health consequences			
Weight gain	29	25	22
Damages the heart	27	13	21
Teeth	16	15	12
Decreased fitness levels	14	10	11
General damage to organs	13	6	9
Lethargy	12	3	7
High blood pressure	11	1	7
Psychological affect	8	1	5
High cholesterol	7	0	4
Skin	6	2	4
Diabetes	5	2	4
Digestive system	3	2	1
Diet Composition			
Moderation	14	3	11
Variation	5	7	2
Natural vs. processed	14	3	3

7.3.1.4 Health Consequences Related to Unhealthy Eating

As shown in table 7.3., across groups the most commonly described health consequence of consuming a diet containing foods high in sugar and/or fat was weight gain, followed by damage to the heart. Participants were also aware that excessive amounts of sugar in the diet can damage the teeth and that an unhealthy diet could lead to decreased levels of fitness and ability to carry out day-to-day activities. Other health effects included general damage to organs (i.e. kidney, liver), lethargy and general weakness, raised blood pressure, diabetes, digestive system problems, and bad skin, although only one or two participants in the ID group discussed these. A few participants, particularly in the ND and PD groups discussed how a poor diet can affect one psychologically, for example affecting mood or self-confidence. A few participants in the ND and PD groups also mentioned raised cholesterol, although few actually knew what cholesterol was.

7.3.1.5 Diet Composition

Responses coded here referred to young peoples' discussions of concepts such as 'moderation', 'variation' and 'processed versus unprocessed foods'. As shown in table 7.3., a number of participants, mainly in the ND and PD groups, discussed the importance of 'moderation' in the diet, stating how it is necessary to consume a small amount of fat in order for the body to function adequately. Although moderation was generally talked of in terms of physical health, one participant went on to discuss the psychological implications of allowing 'forbidden foods' in moderation. Also discussed, but less frequently was the concept of 'variation', where no single food can provide all the essential nutrients that the body needs but that we need to consume a variety of foods. Finally a large number of participants in the ND group discussed the importance of avoiding processed foods (takeaways, microwave meals) and instead aiming to eat foods in their natural state ('homemade' food), as did a few participants in the other groups.

7.3.2 Section 2: Understandings of Healthy and Unhealthy Foods

In section 2, participants' explanations for classifying foods as healthy or unhealthy were elicited. The various methods used to elicit this knowledge were discussed in section 6.9.1., but briefly participants were presented with seven A5 colour photographs illustrating a food item that they were required to sort into 'healthy' and 'unhealthy' foods.

Participants were required to give a rationale for classifying a food as healthy or unhealthy and to discuss any effects it may have on the body. The photographs depicted fruit, milk, a chocolate bar, a fizzy drink, white bread, red meat, and fish. These food items were considered to be representative of the main government healthy eating guidelines of eating plenty of fruit and vegetables, eating plenty of starchy foods, consuming some protein-rich foods and some milk and dairy foods, and finally consuming just a small amount of foods high in fat, salt and sugar. Participants' responses were coded into five major categories displayed in table 7.4. (see section 5.10.5 for details on coding scheme) alongside the number of responses coded at each level by group and example responses. Again, the non-disabled group were the most knowledgeable, followed by the PD group and lastly by the ID group.

7.3.2.1 Foods Classified as Healthy and Unhealthy

All participants classified fruit and milk as healthy, and chocolate and fizzy drinks as unhealthy. However, several participants acknowledged that milk can be fattening and should be consumed in moderation (ND: 8, ID: 6, PD: 6). With regards to fish, only three participants in the ID group and one in the PD group classified fish as unhealthy. Three participants in the ND group also discussed the high fat content of some types of fish and how it should therefore be eaten in moderation. With regards to bread, more of the ID and PD groups believed that white bread was healthy than in the ND group (ND: 3, ID: 16, PD: 11). However, the majority of participants were aware of the healthy eating message 'eat more wholemeal foods', illustrated through their responses that brown bread is better (ND: 24, ID: 18, PD: 18). Again, several participants in the ND and PD group discussed the importance of eating bread in moderation, as it is a rich source of carbohydrate which can lead to weight gain. With regards to red meat, a larger proportion of the ND group considered red meat to be healthy than in the ID and PD groups (26 participants versus 9 and 12 participants respectively). Six participants in the ND and PD groups and three in the ID group believed that red meat had both healthy and unhealthy qualities, discussing the idea that meat is healthy, but because of its high fat content, should be consumed in moderation.

7.3.2.2 Explanations for Classifying Foods as Healthy or Unhealthy

Participants' responses were coded into the five major categories described in table 7.4. As predicted, when participants were asked to explain their decisions to classify foods as healthy or unhealthy, there were differences across the three groups, with the ID group giving less sophisticated explanations. For example, when explaining why fruit and milk are healthy, the majority of the ND and PD groups gave a Level 4 response; that is they were able to cite an inherent feature of the food item that was healthy and discuss its effect on the body. Although a number of responses from the ID group were coded here, they were different from the ND and PD groups as they referred to the health benefits of fruit or milk by discussing the absence of unhealthy qualities (such as fat and sugar); participants could not provide examples of anything specific about fruit that would lead to it being healthy, apart from the negation of its unhealthy properties. On the other hand, participants in the ND and PD groups were also able to discuss the presence of healthy qualities, such as vitamins and fibre in fruit, or calcium and protein in milk. The majority of the ID groups' responses were coded at Level 2 where participants referred to an inherent healthy quality of the food or Level 3 where participants described a positive effect that consuming fruit or milk would have on the body, but were unsure as to how this occurred.

Differences across groups in explanations for classifying foods as unhealthy were less marked; participants seemed to be better at explaining why we should avoid unhealthy foods than why we should eat healthy foods. In the ID group, the majority of responses for classifying chocolate and fizzy drinks as unhealthy were coded at Level 4 (describe both an inherent unhealthy feature of chocolate and/or fizzy drinks and link it with a specific effect on the body). Although a number of the ND and PD groups' responses were also coded here, the majority of ND participants were able to give a more specific and detailed explanation (Level 5). There was more variation in the explanations given for why fish, red meat and bread are healthy/unhealthy, suggesting participants were less certain about the health properties of these foods. The majority of the ND groups' responses referred to an inherent feature of fish, red meat or bread and discussed its effect on the body (Level 4 response). A substantial number of the ID and PD groups' responses were also coded here. However participants in the ID group once again focused on the absence of unhealthy qualities, such as fat/sugar, when explaining their classifications. A few participants in the ND group also discussed how animal fats (found in red meat) are high in saturated fat which can cause damage to the arteries, and therefore lead to heart disease (Level 5).

Table 7.4: Participants' Explanations for Classifying Foods as Healthy/Unhealthy

		Group			Example quote
		ND	ID	PD	
Level 1 - Don't know/ circular	The participant discusses an evaluative aspect of the food, or identifies the sensory characteristics of the food, non-characteristic aspects of the food, derivatives or personal preference.				
	Fruit	0	4	0	“It’ got lots of juice”
	Milk	1	1	0	“It’s cold”
	Chocolate	0	1	0	“Don’t know”
	Fizzy drinks	0	0	0	-----
	Fish	2	8	2	“Fish is good for you”
	Red meat	5	3	5	“It’s from cows”
	Bread	2	3	3	“It tastes good”
	Brown bread	7	1	4	“The ingredients”
Level 2 - Nutrient Content of Food	Participant refers to an inherent healthy or unhealthy quality of the food, for example fat, protein, sugar, yet is unable to offer any explanation of how this interacts with the body.				
	Fruit	1	8	1	“It’s packed full of vitamins”, “there is no fat”
	Milk	3	10	2	“Milk has protein in it”, “vitamins”, “it’s got high levels of calcium”, “it doesn’t have much fat”
	Chocolate	0	4	2	“That’s full of sugar”, “chocolate is very high in fat”
	Fizzy drinks	0	5	0	“Got loadsa sugar”, “gas”
	Fish	4	2	2	“Fish contains protein”, “essential oils, I think they’re called omega something?”
	Red meat	6	12	8	“red meat is high in protein”, “It doesn’t contain a lot of fat”, “all fat”
	Bread	1	5	2	White bread: “loaded with sugar”, “it has wheat in it”, “calcium”, “low fat food”.
	Brown bread	7	7	7	Brown bread: “wholegrain” “has fibre and stuff”, “vitamins”, “bread is high in carbohydrates”
Level 3 - Effect on Organ	The participant mentions a specific effect on an organ or the body, yet offers no explanation to how this occurs.				
	Fruit	3	11	6	“Fruit is good for teeth”, “it helps you lose weight”, “good for concentration”.
	Milk	7	12	6	“good for bones”, “teeth”, “makes you grow”
	Chocolate	0	1	2	“You’d get real fat”, “damages your teeth”, “will make your heart go bad”
	Fizzy drinks	0	2	0	“damages your teeth”, “ you’d put on weight”
	Fish	6	7	7	“Good for the brain”, “helps the heart”
	Red meat	3	1	2	“Makes sure your blood cells are healthy”, “makes your muscles strong”, “to help you grow”
	Bread	0	4	2	“White bread is good for growing”
	Brown bread	0	3	2	“The heart” “looks after your digestion”

Table 7.4 continued over

Table 7.4: Continued.

Level 4 - Link Between Content and Organ	<i>The participant is able to describe both the inherent healthy or unhealthy feature of the food and links this with a specific effect on the body</i>				
	Fruit	25	6	16	"Vitamins help the body fight infections", "protein, so you heal properly", "no fat, so you don't put on weight" "low in sugar...helps your teeth"
	Milk	18	6	15	"Calcium helps to build strong bones and teeth", "calcium is good for growth".
	Chocolate	14	23	15	"Chocolate has a lot of fat and sugar, damages your teeth, or cause you to put on weight"
	Fizzy drinks	17	22	21	"Full of sugar, can rot your teeth", "the caffeine, makes you high", "The oils, good oils, they help your hair and nails", protein is good for building muscle", "no fat in fish, that's good for the heart", "has calcium for bones"
	Fish	17	9	10	"It has protein for growth", "hasn't it got iron..helps your blood stay right", "has a lot of fat and can damage the heart"
	Red meat	18	16	14	"Fibre in it keeps you regular", "all the sugar in white bread, can make you fat and that would damage your heart"
	Bread	0	4	4	"Brown bread has a lot of fibre which keeps you going to the toilet, you know, your bowels healthy", "grains are good for the heart", "carbohydrates for energy"
	Brown bread	11	7	5	
Level 5 - Specific Link Between Content and Organ	<i>As above, but the participant is able to give a specific and detailed explanation</i>				
	Fruit	0	0	0	-----
	Milk	0	0	0	-----
	Chocolate	15	0	4	"The fat would damage your blood vessels and heart, and that would lead to a heart attack"
	Fizzy drinks	12	0	2	"All that sugar would cause you to put on weight and that would put extra strain on your heart and other organs. If your organs are not working properly, like getting enough blood or too much sugar, they'd get diseased and stop working...like you might get diabetes or have a heart attack, you might get resistant to sugar"
	Fish	0	0	1	"It's full of oils which keep the blood vessels healthy by lowering cholesterol and therefore preventing heart disease".
	Red meat	0	0	1	"Foods that are from animals, they have animal fats and they're high in saturated fat which can lead to heart disease... by causing damage to the arteries"
	Brown bread	1	0	0	"It can help to prevent heart disease by helping to lower cholesterol"

A number of participants in each group identified an inherent feature of fish, red meat or bread that was healthy/unhealthy (Level 2) or described associations between consuming these foods and an affect on an organ/body process (Level 3). The fact that fish was a good source of healthy or essential oils was discussed by participants in the ND group, and one participant in the PD group also discussed how these oils can help keep the blood vessels healthy and therefore prevent heart disease (Level 5). One participant in the ND group discussed how fibre in brown bread can help to prevent heart disease by helping to lower blood cholesterol.

7.4 Alcohol Knowledge

7.4.1 Section 1: Spontaneous Beliefs about the Effects of Alcohol

In order to tap into participant's spontaneous beliefs about the effects of alcohol, an open-ended format was used. Participants' beliefs about why people might choose to drink alcohol and its positive and negative effects were explored. Responses were separated into those that referred to alcohol's effects on the body and those that referred to non-health related outcomes.

7.4.1.1 Beliefs about the Health Effects of Alcohol Consumption

Participants' beliefs about the effects of alcohol are shown in table 7.5. All participants named at least one effect that alcohol can have on the body, and overall the ND group named more health affects that the PD group, who in turn named more than the ID group. The most common health affects discussed were on the brain, liver, movement/co-ordination, the heart and cognition/memory. The biggest difference between groups was that the ND group discussed alcohol's affect on the brain and senses (speech, hearing and eyesight) more frequently than the other two groups. A higher number of the ND group and PD group also understood that alcohol can cause vomiting and may damage the stomach. Other health effects of alcohol were damage to the kidneys, poor skin, poor circulation, decreased reaction time and effects on the bladder, although these effects were less frequently discussed by participants in the ID group. A small number of participants also mentioned becoming lethargic and weak (ND: 2, ID: 3, and PD: 2), getting a headache (ND: 2, ID: 2, and PD: 2), decreased ability to perform sexually (ND: 3 ID: 1 and PD: 1). Sleep problems, dehydration, effects on the pancreas, nervous system and impaired healing were also discussed by one or two participants from the ND and PD groups. Young people expressed virtually no awareness that chronic alcohol use can cause mouth disease (this was also covered in the quantitative phase of data collection) with only one participant from the ND group mentioning this. It was also interesting that over 10 participants in the ID groups discussed how alcohol could damage the lungs. Although this is actually correct when participants' responses were probed it became clear that these young people were associating the negative health effects of other behaviours, such as smoking, with alcohol consumption. This is a finding that has been reported elsewhere with younger children overgeneralising from a behaviour they are more familiar with (Sigelman et al., 2000).

Table 7.5: Consequences of Alcohol Consumption

	No Disability	Intellectual Disability	Physically Disability
	<i>n</i> 28	<i>n</i> 24	<i>n</i> 23
General			
Non-Specific Illness / Disease	8	10	5
Effects Everywhere	11	4	7
Death	1	5	3
Specific Site			
Brain	23	12	13
Liver	22	15	15
Movement And Co-Ordination	16	11	10
Cognition / Memory	12	13	8
Heart	13	14	9
Senses	19	7	10
Vomiting	10	5	14
Stomach / Ulcers	12	1	7
Kidneys	9	7	7
Skin	7	1	4
Circulation/Blood	8	0	5
Reactions	7	0	6
Bladder / Micturition	6	1	3
Lungs	0	10	0
Non-Health Outcomes			
Removal of Inhibitions	20	14	16
Coping	18	10	9
Positive Mood	15	10	8
Negative Mood	10	12	15
Social Situations	10	5	5
Excitement	12	8	6
Personality Change	8	13	10
Conformity	7	0	4
Harm to self/ others	5	3	2
Relationships	4	1	2
Work Related	2	0	1
Sex Related	2	0	1

7.4.1.2 Beliefs about Non-Health Related Effects of Alcohol Consumption

The majority of participants were able to cite at least one positive or negative non-health related consequence associated with alcohol consumption as shown in table 7.5., with only 2 participants in the ID group giving no response. The ND group mentioned more positive outcomes than the PD group, who in turn mentioned more than the ID group. All groups endorsed a similar number of perceived negative outcomes of drinking alcohol. Across the majority of expected outcomes that were mentioned, a higher proportion came from the

Table 7.6: Non-Health Consequences of Alcohol Consumption: Examples of responses given by each group**Removal of Inhibitions**

"But it makes people feel good, gives them a sense of confidence, it might be false confidence, but it's still there, make you seem more outgoing".

No disability, female

"Because it can cause you to lose your inhibitions, when you sober up your inhibitions are back and basically faced with things that you might have done, like the A&E department, either through alcohol or attacked by someone with alcohol".

No disability, male

"If you drink too much it makes you do things that make you embarrassed".

Intellectual disability, male

Positive Mood/Negative Mood

"Yes your mood is the first thing that gets affected. Some people can get very aggressive when they take alcohol, or they can get very happy, singing and dancing and all that rubbish, stripping sometimes! You get very sad as well, a flash in your head something that happened in the day, a depressing feeling that may come over you, and like I said you might harm yourself, it depends on the person, if it's a very shy quiet person, er, one that maybe doesn't drink a lot, if he drinks it his depression would continue with the drink, and the more he drank, the more lonely and downy he gets because he's getting tired, restless and that, or some people if they drink a wee bit they feel more energetic, they will be dancing about like I said, and they feel more able to do stuff and that".

Intellectual disability, male

Personality Change

"It can make people aggressive, there is no telling how it might affect someone, after all it's a drug that affects the brain".

No disability, female

"Bad mood swings, start snapping at people, inside your mind you just snap. It makes you horrible, rotten and miserable".

Intellectual disability, female

"It turns your nature, it turns your nature straight away if you've took too much.....like you might get aggressive, you might start using terrible language at people. And also, people might start knowing you as a badder person 'cos, they're seen you like that, and they might not want to talk to you when you're sober because they're seen your nature, when your drunk".

Physical disability, male

Harm to Self / Others

"Obviously there is drink-driving, the drivers among the drinkers, probably get in the car, that's probably the most dangerous of them all, 'cos god knows what'll happen when they're on the roads".

No disability, female

"If you have a lot, it might mess your head up, might go for a drive and crash or something, knock someone down, or turn violent on people".

Intellectual disability, female

Coping

"Makes you think more, get things off your chest, your problems off your chest, like if you fell out with your girlfriend and your arguing, and you have a drink, it can calm you down a bit".

Intellectual disability, male

"It can make them feel more positive and stuff about themselves, and it also, its maybe a way, like you may feel better, it makes people feel a lot better than they, than, when sometimes they are down and all that. And if anything's happened for instance, like bad times, if they have had any bad times, if they have been shocked, aye if you're in shock".

Physical disability, male

Heightened Emotions

"People could go on downers if they've had a bad day or problems at home. They drink to get rid of that and they just end up getting more emotional, like someone that's ever lost relative or something, you always see them crying in the corner at parties".

No disability, female

"If you take alcohol you are eliminating problems in your realistic life, but through the influence of drugs you are heightening the problem and you get more upset. When you drink you become more focused on the problem in the subconscious mind". 108

Social Situations

"Just because, at celebrations, to socialise, maybe they're in a group, just celebrating and socialising; to have a good time".

Intellectual disability, male

"In Scotland it's the done thing, something you do socially and you're isolated if you don't. You may get a dependency on it, not an addiction, to be confident and sociable".

No disability, male

Conformity

"It can give them confidence, it could say, it's trying to keep in with the trend, peer pressure, being forced to drink it".

No disability, female

"They're a bit more accepted if they can have a laugh or make people laugh".

No disability, male

"Maybe just about social inclusion. If they are out and other people are drinking, they will drink with them".

Physical disability, male

Relationships / Work

"You can get an addiction to it, you can lose family, friends, push people away from you, lose your job. That's how it can make people feel bad"

No disability, male

"You get sad, people want to fight and get upset. You can have family problems and divorce; divorce because of the alcohol".

Intellectual disability, male

ND group. The PD groups' responses however, were more similar to the ID group than the ND group.

The most frequent beliefs participants mentioned about the effects of alcohol consumption were lowered inhibitions, its use in helping people cope with stressful situations, altering mood, and helping to facilitate one's enjoyment and sociability (see table 7.6 for example responses). The main differences across groups were that the ND group were more likely to mention using alcohol to help cope, for example dealing with stress and negative emotions. The ND group also talked more about drinking for social purposes such as celebrating or at parties. On the other hand, participants in the ID and PD groups were more likely to discuss negative personality changes that happen as a result of drinking alcohol, and in particular becoming angry and aggressive. It was interesting that although the ND group described lowered inhibitions both positively (having a better time, feeling more confident) and negatively (later regret, embarrassment), the ID and PD groups focused more on the negative consequences. A few participants in the ND and PD groups also discussed how people often drink because of peer pressure or to be accepted by others, although this was not mentioned by the ID group. Several participants in the ND group also discussed how alcohol use is deeply rooted in Scottish society and as such is 'a way of life' for many people. The remaining effects of alcohol were discussed by a few participants in each group, including accidental harm to self and others, such as drink driving incidents, work and relationship problems, and increased likelihood to engage in risky sexual behaviours.

7.4.2 Section 2: Understanding of Alcohol's Effect on the Body

In section 2, participants' understanding of alcohol's effect on the body were elicited. Participants were presented with six A5 colour photographs each illustrating a possible outcome of drinking alcohol. Participants were required to sort the photographs into two piles, one pile for outcomes they thought would happen and one pile for outcomes they thought would not. They were asked to give a rationale for each choice they made. The photographs depicted behaviours that were considered to be representative of different effects alcohol can have (i.e. short-term, long term, physical and emotional effects), and included vomiting, memory loss, problems with co-ordination/balance, effects on mood, vision, and weight. Participants' responses were coded into five major categories displayed

in table 7.7. (see section 5.10.5 for details on coding scheme) alongside the number of responses coded at each level by group and examples of responses.

7.4.2.1 Expected Outcomes Associated with Alcohol consumption

All participants stated that alcohol could cause vomiting and all of the ND and PD groups stated that memory, coordination/balance and mood can be affected, as did the majority of participants in the ID group. The majority of participants also believed that vision and weight would be effected, although a few from each group said that they would not.

7.4.2.2 Explanations for Alcohols Effects on the Body

Participants' responses were coded into the five major categories described in table 7.7. When participants were asked to explain their decisions about whether alcohol caused a specified outcome, as predicted there were differences across the three groups, with the ID group giving less sophisticated explanations than the other two groups. For example, the majority of the responses given by participants in the ID group were coded at Level 2, where they discussed either how a particular constituent of alcohol (such as 'acid', 'sugar' or 'gas') or the amount, speed or time period over which the alcohol is ingested has an effect on the body. A few participants in the ID group also discussed how alcohol causes damage to an organ or the body as a whole or mentioned that the brain was affected, but were unable to specify how this happened (level 3). A large number of participants in the ND and PD groups discussed how the brain was affected, but were unable to specify how this happened (level 3). Several participants however were also able to articulate more specifically how the brain was affected by alcohol, for example that alcohol depresses parts of the brain and this can lead to behavioural changes (level 5). However, a number of responses in the ND and PD groups were still coded at level 3, where damage to an organ or the body was discussed, but with no understanding of how. It appeared that mood was the hardest of all effects to explain, with 10, 16 and 13 participants in the ND, ID and PD groups respectively, not being able to offer a response.

Table 7.7: Participants' Explanations for Alcohol Effects – Structured Questions

		Group			Example quote
		ND	ID	PD	
Level 1 – Don't know/circular	Where the participant cannot explain his or her response, restates the question or mentions phenomenon associated with drinking alcohol.				
	Vomiting	2	3	0	"It's the alcohol in it, makes you sick"
	Memory	6	7	4	"I don't know"
	Coordination/Balance	2	6	2	"I don't drink, I don't like alcohol"
	Mood	10	16	13	"Yeah it would effect your mood"
	Vision	5	6	4	"I like beer"
	Weight	4	2	5	"If you drink, that would effect your weight"
Level 2 – Quantity, speed, duration or content	Where an effect is attributed to the amount of alcohol ingested, the speed at which it is ingested, or the time period over which it has been taken OR the contents of the alcoholic beverage, such as 'chemicals', 'acid' or 'gases'.				
	Vomiting	5	18	6	"It's all the fizz, it makes you sick"
	Memory	0	10	0	"If you drink too much"
	Coordination/Balance	2	8	2	"By drinking lots, too quickly"
	Mood	2	2	1	"The chemicals in alcohol would affect your mood"
	Vision	0	4	0	"The acid, yeah, it'd be the acid"
	Weight	13	18	6	"The sugar"
Level 3 – Effect on Organ	The participant refers to how alcohol damage to the organ or body as a whole, but this is not specified.				
	Vomiting	4	3	3	"It would damage your stomach, just by drinking it, and make you sick"
	Memory	4	0	1	"It would go into the head, and you'd forget things"
	Coordination/Balance	9	3	5	"It would damage his eyes, and he'd fall over"
	Mood	7	2	3	"It goes into your blood and makes you high"
	Vision	4	6	4	"Goes for the eyes, damages them"
Level 3 – Effect on Brain	The participant acknowledges the role of the brain in producing the specific effect, yet cannot articulate how.				
	Memory	12	5	12	"The alcohol goes to the brain, and you start losing memories"
	Coordination/Balance	10	5	8	"If you drink too much, it you'd fall over...cos' the alcohol has entered the brain"
	Mood	5	0	2	"Its the brain"
	Vision	9	4	7	"It would damage the brain"
Level 4 - Link Between Alcohol and Behaviour - The participant describes specifically how or why an organ is damaged or involved in producing the effect, but does not mention the brain.					
	Weight	10	0	6	"All the sugar in the alcohol, that would make you fat"
Level 5 - Specific Link Alcohol & Brain	The participant is able to articulate how alcohol affects the brain, and how in turn this impacts on the behaviour/effect in question				
	Vomiting	17	0	11	"The alcohol would get into his brain and kill his brain cells"
	Memory	6	0	3	"shut down parts of his brain, then you don't remember stuff"
	Coordination/Balance	5	0	3	"It'd effect the movement part of your brain, so you'd fall over"
	Mood	4	0	1	"Its suppresses the brain, and you get really relaxed"
	Vision	6	0	4	"It travels to the eyes, the brain, stops it working right and then it cant send signals to the eyes right"

7.5 Pregnancy and Contraception Knowledge

7.5.1 Section 1: *Spontaneous Beliefs about Pregnancy and Contraception*

Participants' understandings about pregnancy and contraception were examined via two open ended questions. Firstly participants' beliefs about sexual reproduction were elicited through the open-ended question *"Can you tell me how someone would get pregnant/make a baby?"* Secondly, participants' knowledge about methods of contraception and their understandings of how these work were examined through their responses to the open-ended question *"Imagine two people wanted to have sex. What could they do to stop having a baby/getting pregnant?"* Both open-ended questions were followed by a series of follow up questions and structured prompts.

7.5.1.1 Beliefs about Sexual Reproduction

Participants' transcripts were examined and one point was awarded if there was evidence of the following seven elements of knowledge as shown in table 7.8: knowledge that (a) the erect penis (b) is inserted into the female's vagina (c) whereupon stimulation experienced during sexual intercourse (d) sperm is released. The sperm then (f) travels inside the female in order to meet with the ova, which (g) if the conditions and timing are right, will be present. Scores ranged from 0-6. Participants were not required to use biological terms in order for credit to be given, but could also make their views known through a combination of the use of visual aids which they could point at and/or discuss using their own names for body parts. Five participants from the ID group pointed to stimuli only and therefore although it appeared that they knew what body parts were involved they could offer no further explanations. This was the case for one of the PD participants. One participant from the ID group stated that something goes into the woman from the man, but would not expand and one participant refused to answer the question, although she was happy to continue with the other sections of the questionnaire. The remaining participants were all able to offer some explanation.

As predicted the ND group demonstrated greater knowledge than the ID group and the PD group. The ID and PD group performed similarly to one another. The vast majority of

participants in the ND and PD groups stated that the penis is inserted into the female/vagina, the penis releases sperm, and the sperm joins with the female ovum/egg to create a baby/embryo. Fifteen participants (68%) in the ID group also mentioned that the penis is inserted into the female and the penis releases sperm; a much lower number discussed the role of the female egg in producing a baby. However, concepts such as the penis has to be erect before sexual intercourse can take place, stimulation of the penis during sexual intercourse is needed to release sperm, and that conception depends on a female ovum/egg being present, were mentioned less frequently by participants in the ID and PD groups compared to the ND group. Therefore, it appeared that the ND and PD groups performed similarly with regard to basic facts about sexual reproduction, however with more advanced concepts, the ID and PD group were more alike.

Table 7.8: Number of Participants Mastering Elements of Knowledge of Sexual Reproduction

	No Disability	Intellectual Disability	Physical Disability
	<i>n</i> 23	<i>n</i> 22	<i>n</i> 23
1. Erect Penis	12	2	3
2. Insert into female	23	15	22
3. Stimulation	7	0	2
4. Releases sperm	23	15	22
5. Fuse with egg	22	5	21
6. If egg present	14	2	6

7.5.1.2 Knowledge about Methods of Contraception

Transcripts were first examined for the number of different types of contraception that participants had heard of. The ND group could name approximately twice as many different types of contraceptives than either the ID or PD groups, who in turned performed similarly to one another. The most commonly discussed method of contraception was the male condom, being discussed by nearly all the ND and PD groups, and over three-quarters of the ID group. Nearly all the ND group mentioned the contraceptive or oral pill, but this was mentioned less often than the condom for the ID and PD groups. The contraceptive injection and the morning after/emergency contraceptive pill were also mentioned by a number of participants in the ND group, but fewer participants in the ID and PD groups. The coil, the Femidom, the diaphragm, the implant and surgical procedures, although

mentioned by a number of participants in the ND group were seldom discussed by the other two groups. The remaining types of contraceptives were only mentioned at most by one or two participants. Abstinence was mentioned by two participants in the ID group only.

Table 7.9: Knowledge about Methods of Contraception

	No Disability <i>n</i> 23	Intellectual Disability <i>n</i> 22	Physical Disability <i>n</i> 23
Mean	4.74	2.27	2.33
Male Condom	21	17	22
Contraceptive Pill	21	14	17
Contraceptive Injection	17	7	7
Morning After pill	12	4	4
Coil	9	1	1
Femidom	8	1	2
Diaphragm	6	1	0
Implant	5	1	1
Surgery Procedure	5	2	1
Spermicide/Sponge	2	0	0
Patch	2	0	0
Natural Rhythm	1	0	1
Abstinence	0	2	1
None	0	2	2

7.5.2 Section 2: Understanding of Pregnancy and Contraception

In section 2 participants were presented with six A5 colour photographs each illustrating a sexually-related behaviour relating to pregnancy. Participants were required to sort the photographs into two piles; one they thought would lead to pregnancy and one they thought would not, and to give a rationale for each of their choices. The photographs depicted three forms of contraception that can help to prevent pregnancy (male condom, contraceptive pill, contraceptive injection), and three myths relating to sex (“You can’t get pregnant the first time you have sex”, “You can’t get pregnant when you’re on your period”, and “If a guy pulls out before he ejaculates you won’t get pregnant”). Participants’ responses to the contraception questions were coded into four major categories displayed in table 7.10. (see section 5.10.5 for details on coding scheme) alongside the number of

responses coded at each level by group and examples of responses. Participants' responses to the questions relating to pregnancy myths are displayed in table 7.11.

7.5.2.1 Pregnancy Prevention

The entire ND group and the majority of the ID and PD groups believed that the condom and the pill could prevent pregnancy. However, there was some confusion about the contraceptive injection, with five participants in the ND group, 11 in the PD group and 13 in the ID group saying either it could not prevent pregnancy or that they were unsure.

7.5.2.2 Explanations for How Contraceptives Work

Of the participants who said the different forms of contraception did not prevent pregnancy, they were unable to offer an explanation as to why beyond the statement that "*they don't*". The majority of participants had a fairly good understanding of how the condom should be used and how it prevents pregnancy. Most of the explanations offered by the ID group discussed how the condom covers the male's penis and prevents sperm from entering the female (Level 3), as did a few from the PD group and one from the ND group. In addition, the majority of the ND and PD groups went on to explain this would prevent sperm from fertilising an egg in the female and therefore would prevent pregnancy (Level 4).

A number of participants across the three groups, but most notably in the ID and PD groups, were unsure how the contraceptive pill would prevent pregnancy. Most of the responses given by the ND group and a few from the PD group discussed how the pill prevented an egg from being released in the female (suppresses ovulation) and/or makes the lining of the womb inhospitable for implantation of a fertilised egg (thickening the mucous around the cervix, preventing sperm from entering the uterus; Level 4). Another explanation given was that the pill causes a 'false period', where the body is forced to think it is pregnant due to the hormones. The contraceptive injection was less well understood compared to other forms of contraception across groups, with none of the ID group and only a small number of the PD group being able to offer an explanation. However, a number of participants in the ND group were able to offer a biological mechanism by which the contraceptive injection prevents pregnancy, giving similar explanations as for the contraceptive pill (Level 4). A few participants in the ID and PD

groups believed that the contraceptive pill and/or injection killed sperm. One participant from the ID group also believed the man took the contraceptive pill.

Table 7.10: Participants' Explanations of how Contraceptives Work

		ND	Group ND	ND	Example quote
Level 1 – Don't know/circular	<i>Where the participant cannot explain his or her response, restates the question or mentions phenomenon associated with sexual activity/behaviour.</i>				
	Condom	0	0	0	"You use that for sex"
	Contraceptive Pill	10	18	15	"I don't know, not heard of that"
	Contraceptive Injection	7	9	7	"It would stop you getting pregnant, that'd be awful"
Level 2 – Isolated facts	<i>Where the participant can cite back facts about contraception, but with little understanding of any biological mechanism of how it works</i>				
	Condom	1	3	0	"The man uses that, on his willy, made of rubber"
	Contraceptive Pill	2	1	1	"You swallow that every day and you wont get a baby"
	Contraceptive Injection	5	0	2	"A jag in the bum, that stops you having babies, women have it"
Level 3 – Isolated agents	<i>The participant begins to discuss how the contraceptive affects internal agents or body parts, such as sperm, eggs, penis, vagina, hormones, but with little understanding of how they enter the body or interact within the body</i>				
	Condom	0	11	5	"It stops the sperm from leaving the man and going into the woman's private area"
	Contraceptive Pill	0	0	5	"Hormones, it's full of hormones and they stop you getting pregnant"
	Contraceptive Injection	3	0	3	"That's full of chemicals and they go round your body and you cannae have kids then"
Level 4 – Biological mechanism	<i>The participant is able to discuss the biological mechanism which stops pregnancy</i>				
	Condom	22	5	17	"It stops the sperm entering the women, and the sperm cant fertilise the egg then"
	Contraceptive Pill	11	1	0	"The hormones, they stop the women releasing an egg, and if there is no egg, there can't be a pregnancy"
	Contraceptive Injection	8	0	0	"It's like the pill, with hormones that suppress ovulation"

7.5.2.3 Explanations for Endorsing or Rejecting Myths: "You can't get pregnant the first time you have sex"

Table 7.11. displays participants' explanations for endorsing or rejecting sexual myths. The entire ND group, three-quarters (18 participants) of the PD group and over half (13 participants) of the ID group knew there was a possibility of conception during first sexual intercourse. All of the ND participants explained that as long as sexual intercourse takes place there is a chance for pregnancy to occur (i.e. for sperm to meet with an egg), as did 14 participant in the PD group, but fewer of the ID group (5 participants). A number of participants in the ID and PD groups were unsure why you cannot get pregnant the first

time you have sexual intercourse (ID: 6, PD: 4), and 2 participants in the ID group agreed pregnancy could occur, but only if '*you did it for long enough*'.

Nine participants in the ID group thought pregnancy was not possible, arguing that sex has to happen on several occasions, for example '*to get used to the sperm*' or to '*do it right*'. Four participants in the PD group referred to the idea that the sexual organs are not functioning properly the first time someone has sex (i.e. sperm is not released), and therefore pregnancy is unlikely.

7.5.2.4 “You can’t get pregnant when you’re on your period”

Participants were asked if they thought that pregnancy could occur if sexual intercourse took place whilst the female was menstruating. Six participants in the ND group, 10 in the ID group and 9 in the PD group believed that pregnancy could not happen. A number of participants in the ID group explained their response by stating that the blood would prevent pregnancy (and infections) occurring, for example stopping the sperm. Several of the ID and PD participants also believed that it was dangerous to have sex whilst the female was on her period, but were unsure as to why this would stop her getting pregnant. While 6 participants in the ND group also wrongly believed that pregnancy could not occur whilst the female was menstruating, their reasoning was at least partly correct. These participants explained that pregnancy could not occur as an egg had already been released and therefore the sperm could not fertilise it. This belief was also endorsed by 4 participants in the PD group.

Of the participants who believed that pregnancy could occur, the majority of the ND group knew that conception was *less likely* than at other times in the female’s menstrual cycle; conversely the majority of the ID and PD groups believed it was *more likely* to occur. This highlights the importance of exploring participants’ reasoning behind their responses. For example, a large number of ND participants stated that although it is unlikely pregnancy could occur whilst a female is menstruating, it is still possible because sperm can survive several days in the female’s body or a second egg may be released, allowing fertilisation to occur. This view was shared by 2 participants in the PD group. However, it should be noted that 7 participants in the ND group and one in the PD group were unsure why they thought pregnancy was less likely.

Table 7.11: Explanations for Endorsing or Rejecting Sexual Myths

	No Disability <i>n</i> 23	Intellectual Disability <i>n</i> 22	Physical Disability <i>n</i> 23
‘You can’t get pregnant the first time you have sex’			
<i>Accept myth</i>	0	9	5
Don’t know	0	4	1
Need to have sex several times	0	5	0
Organs do not function properly first time	0	0	4
<i>Reject myth</i>	23	13	18
Don’t know	0	6	4
Is a chance if intercourse takes place	23	5	14
Is a chance if intercourse lasts long enough	0	2	0
‘You can’t get pregnant when you’re on your period’			
<i>Accept myth</i>	6	10*	9
Don’t know/dangerous	0	5	5
Egg has already been released	6	0	4
Blood prevents pregnancy	0	5	0
<i>Reject myth</i>			
<i>‘Conception is more likely’ because...</i>	2	6	11
Egg is ready/ optimal environment	0	3	8
Blood doesn’t stop sperm	0	2	1
Don’t know	2	1	2
<i>‘Conception is less likely’ but possible because..</i>	15	0	3
Sperm can survive in the body	5	0	2
A second egg may be released	3	0	0
Don’t know	7	0	1
‘If a guy pulls out before he ejaculates you won’t get pregnant’			
<i>Accept myth</i>	4	20	17
Don’t know	1	11	7
No sperm present	3	9	10
<i>Reject myth</i>	19	2	6
Don’t know	0	0	4
Proximity of sperm to vagina	4	2	1
Presence of pre-ejaculatory semen	14	0	1
Sperm survival	1	0	0

* Six participants said they did not know

A number of participants in the ID and PD groups believed that pregnancy was *more* likely to occur whilst a female is menstruating, explaining that this was when the female releases an egg, that this provides the optimal environment for conception to occur, or that blood does not stop the sperm. The two ND participants who believed pregnancy was more likely were unsure why, as was one PD participant.

7.5.2.5 “If a guy pulls out before he ejaculates you won’t get pregnant”

There was much confusion in the ID and PD groups as to whether conception would occur if the male withdraws his penis before ejaculation; only two participants in the ID group and six in the PD group thought that this could lead to the female becoming pregnant, in comparison to 19 participants in the ND group. ND participants explained their responses by either referring to the presence of pre-ejaculatory semen (pre-cum) released during sexual activity and which may contain sperm, or acknowledging the fact that if the penis/sperm comes close to the vagina, there is a possibility of pregnancy occurring. Participants in the ID and PD groups were poor at answering this question.

7.6 HIV knowledge

7.6.1 Section 1: Spontaneous Beliefs about HIV transmission

Participants’ salient beliefs about how HIV is transmitted were examined through the open-ended questions, “*How would someone get HIV/AIDS?*” and “*How would it get from one person to another?*” Overall the interviews obtained a similar pattern of results to those from the structured HIV questionnaires, with the ND group endorsing more accurate beliefs about HIV than the PD group, with the ID group demonstrating the least knowledge. However, each group held misconceptions about HIV. Responses were separated into possible routes of HIV transmission and understandings about the mechanisms of HIV transmission. Four participants in the ID group and two in the PD group, although having heard of HIV/AIDS did not know how it was transmitted. Their transcripts were still included in the analysis as through the structured questions, these participants were able to make known the knowledge they had.

7.6.1.1 Knowledge of HIV Transmission

As can be seen from table 7.12., the most common routes mentioned were sexual intercourse, blood and needles. Whereas the entire ND group discussed how HIV can be transmitted through sexual intercourse, a smaller number of the PD group did, and even fewer of the ID group. When participants were asked to elaborate on how sexual intercourse could transmit HIV, only a small number in each group mentioned the exchange of bodily fluids (i.e. sexual fluids had to enter the bloodstream). Most responses

about sexual transmission were unspecific. An almost equal number of participants in the ND and PD group mentioned that HIV can be transmitted by blood (17 and 15 participants) or needles (11 and 8 participants), but only two participants in the ID group mentioned this. Again, although the majority of responses given by participants in the ND group discussed how blood has to be internalised for HIV transmission to occur, for example through both persons involved having an open wound, or through blood on the needle being passed into the recipient's bloodstream. Responses from participants in the PD and ID groups were less sophisticated, for example suggesting you only need to come into contact with blood for HIV to be transmitted.

Table 7.12: Knowledge of Routes and Mechanisms of HIV Transmission

	No Disability <i>n</i> 24	Intellectual Disability <i>n</i> 20	Physically Disability <i>n</i> 23
Total Number			
Routes of Transmission			
Sexual Intercourse	24	10	15
Blood	17	2	15
Needles	11	2	8
Inherited or in-utero	6	0	0
Casual Contact	3	5	4
Specific Groups	1	4	3
Third World Countries	7	1	1
Mosquito Bite	1	0	1
Hygiene	0	1	0
None	0	4	2
Mechanisms of Transmission			
HIV is present	20	11	11
In sufficient quantity	14	1	4
Enters body	23	11	16
Enters bloodstream	16	1	5
Specific environment	5	0	2

A few participants from each group believed that HIV can be transmitted through casual contact such as kissing, sharing/swallowing saliva or sharing the same eating or drinking utensils. A few participants, particularly in the ID and PD groups, stated that certain groups of people were more vulnerable to HIV, including homosexuals, males and prostitutes. However, these participants could not explain why they thought this might be true. More participants in the ND group thought that HIV was particularly an issue in third world

countries such as Africa and could be passed on from mother to child either during pregnancy or birth.

7.6.1.2 Knowledge of the Mechanisms of HIV Transmission

Each transcript was considered as a whole to examine participants' understandings of HIV transmission. Participants' responses were separated into five categories, depending on whether participants demonstrated evidence that in order for infection to occur (a) HIV must be present (b) in sufficient quantity, whereupon it must (c) get into the body in order for it to d) enter the bloodstream and replicate and that HIV can also only (e) survive under certain specific conditions. As can be seen from table 7.12., the ND group demonstrated greater knowledge than the ID group and the PD group, whereas the ID and PD groups performed similarly to one another.

The majority of the ND group and approximately half of the ID and PD groups discussed how the persons involved must already be infected (with HIV). In other words they discussed how the HIV virus had to present, for example in blood, for infection to occur. A large number of participants in the ND group discussed how HIV is only found in specific bodily fluids, for example that it is not found in saliva, tears, urine, sweat or faeces or at least not in quantities sufficient to infect another person. This was infrequently mentioned by the ID and PD groups. The majority of the ND group also understood that HIV needs to enter the body to cause infection, for example through an open wound or one of the body openings. In addition, a large number of these participants went on to discuss how HIV has to enter the bloodstream of the person to cause infection (i.e. blood has to mix). Fewer participants in the PD group, and even fewer in the ID group, discussed how HIV has to enter the body to cause infection and only a few mentioned the HIV entering the bloodstream. The difference between responses that referred to HIV entering the body and those that referred to HIV entering the bloodstream, although subtle, is important as the latter reflects a more sophisticated understanding about the biological mechanism of HIV infection. Only a small number of participants in the ND and PD groups mentioned that HIV can only survive under very specific conditions, such as in human blood, and dies almost immediately upon contact with air, water, or chemicals.

7.6.2. Section 2: Understandings and Misunderstandings about HIV

In section 2 participants were presented with six A5 colour photographs each illustrating a behaviour that participants were required to sort the photographs into two piles; the behaviours they thought could lead to HIV infection and those that could not. They were asked to give a rationale for each of their choices. The photographs depicted three possible methods of HIV transmission (through sharing a needle, having sexual intercourse and through an open wound) and three highly improbable behaviours (kissing, hugging or sharing a swimming pool with a person with HIV). Participants' responses were coded into five major categories displayed in table 7.13. (see section 5.10.5 for details on coding scheme) alongside the number of responses coded at each level by group and examples of responses.

7.6.2.1 Beliefs about routes of HIV transmission

Across groups the majority of participants recognised that sharing needles, sexual intercourse and having an open wound were major routes of HIV transmission. Slightly fewer participants believed an open wound would transmit the virus. Most participants in the ND and PD groups also knew that HIV could not be transmitted via hugging or through a swimming pool. Whilst a large number of the ID group also shared this knowledge, these participants also held more misconceptions about HIV than in the other two groups. Across groups there was some confusion as to whether HIV could be transmitted through kissing. The majority of participants in the ND group said you could not get HIV through kissing, but more participants in the ID and PD groups believed you could.

7.6.2.2 Explanations for Classifying Behaviours as Risky or Non-Risky

Participants' responses were coded into the five major categories described in table 7.13. With regard to sharing needles and open wounds, the majority of the ND participants' responses were coded at Level 5. This meant that they referred to how these behaviours lead to the internalisation of high-risk bodily fluids. In other words they understood that

Table 7.13: Participants' Explanations for Classifying Behaviours as Risky or Non-Risky

Group ID				Example quote	
ND	ID	PD			
Level 1 - Don't know/ circular	The participant cannot explain his or her response, restates the question or mentions phenomenon associated with having HIV as if it were its cause.				
	Sharing Needles	2	5	1	“By using needles”
	Sexual intercourse	2	2	2	“If you have lots of sex”
	Open Wound	0	2	0	“I don't know, you just would”
	Kissing	3	6	5	“That'd give you the AIDS”
	Hugging	1	9	6	“You definitely get it from hugging someone”
	Swimming Pool	1	10	4	“from being in the water”
Level 2 - Casual contact or contagion	The participant overgeneralises from knowledge of other illnesses (i.e. casual contact with a person with HIV as sufficient to transmit HIV).				
	Sharing Needles	0	4	2	“The germs on the needle”
	Sexual intercourse	0	5	2	“If his private bits touch hers, being naked together”
	Open Wound	0	6	1	“Touching the inside”
	Kissing	0	0	0	-----
	Hugging	3	1	5	“Cos they're touching each other, they're close”
	Swimming Pool	0	1	0	“Cos their not wearing much clothing, they bump into one another”
Level 3 – Bodily Fluids	The participant mentions high-risk bodily fluids, however fails to mention agents must get into body/act upon body in particular neither way, nor what the causal agent does or why. (i.e. knowledge appears to be rote).				
	Sharing Needles	1	0	4	The blood on the needle, that's got the HIV”
	Sexual intercourse	2	0	1	“You get it from sex, the fluids”
	Open Wound	2	6	6	“The blood, if you touch the blood”
	Kissing	0	0	0	-----
	Hugging	3	1	6	“No, cos' there's no blood involved”
	Swimming Pool	0	2	6	“If they bled into the pool”
Level 4 - Internalisation of the Agent	Begin to describe the internalisation of the agent , causal agents act on the body or get into the body and do something specific to the body				
	Sharing Needles	3	19	11	“You put a dirty needle into your arm and you get AIDS”
	Sexual intercourse	12	2	10	“Fluids go into you, from his penis, the sperm”
	Open Wound	5	3	9	“Blood from the cut goes into his body and causes HIV”
	Kissing	2	1	4	“There would need to be blood, so the blood would go into you”
	Hugging	3	3	2	“No, cos' that's external, HIV has to go inside”
	Swimming Pool	2	0	5	“If blood could get into your mouth I suppose”
Level 5 – Internalisation into the bloodstream	The participant understands that the internalisation of high-risk body fluids is necessary for transmission, for example into bloodstream.				
	Sharing Needles	18	1	5	“The blood on the needle would get put into your bloodstream, and then HIV would be in your body and kill you”
	Sexual intercourse	7	0	3	“The fluids, the vagina juices and sperm get exchanged and HIV enter the bloodstream”
	Open Wound	15	0	4	“HIV is in the blood, and if you've a cut, it can get into your blood”
	Kissing	10	0	2	“No, cos blood has to exchange, your blood and theirs mix”
	Hugging	13	0	2	“It has to be fluids mixing, like blood and stuff”
	Swimming Pool	12	0	2	“That wouldn't happen, blood would just go into pool, it needs to go into the persons bloodstream to cause HIV”

blood/semen must travel from the inside of one person to the inside/bloodstream of another person. Although for sexual intercourse more responses were coded at Level 4, with mentions of sexual fluids entering the body but no mention of the virus entering the bloodstream. Most of the PD groups' responses were coded at Level 4.

The majority of the ND group were able to use their understanding of how HIV is transmitted to reject the myths they were presented with, including the myth that HIV can be transmitted through kissing, hugging or using the same swimming pool as someone who was HIV positive. Responses given by the PD group were much more varied across levels, for example discussing how kissing, hugging or sharing a swimming pool could not transmit HIV as HIV is not found in saliva (level 3), and/or that bodily fluids other than saliva (i.e. blood, semen) needed to enter the recipients body for infection to occur (level 4). With regard to the ID group there was much variation in responses, with many participants being unable to explain their answers. Some discussed how physical contact with or proximity to a person with HIV is sufficient to transmit HIV. For example, physical proximity to someone during sex in the form of 'naked touching' was viewed as dangerous. A few participants were able to discuss the high-risk nature of bodily fluids such as blood, but did not acknowledge that these need to be internalised by the recipient for infection to occur, for instance saying that HIV could be absorbed through the skin. A number of participants in the ID group however did discuss the internalisation of bodily fluids, although not into the bloodstream, when discussing how sharing needles transmits HIV (level 4).

Nine participants in the ID group and four in the PD group also believed that HIV was caused by having numerous sexual partners or frequently engaging in sexual intercourse. However, when these participants were prompted for further explanations, only two gave a response which suggested that having sexual intercourse with different partners puts you at increased risk of catching HIV as opposed to the act of having 'too much sex' *per se*. One participant also believed that HIV is carried on condoms and therefore you are less likely to get HIV if you *do not* use protection. It was also interesting to note that although the majority of participants across groups were aware that both males and females are vulnerable to HIV, a number of participants were unsure if or how a woman could pass it onto a man. This misconception seemed to stem from the fact that although participants could conceptualise how HIV can pass from a man to a woman/another man via semen,

understanding how it is passed on via other bodily fluids, such as vaginal fluid is more difficult, particularly if participants have a poor sexual understanding. Other misconceptions held by a few participants in the ID and PD group were that germs on a needle or in a cut could cause HIV to be transmitted, suggesting that these participants were overgeneralising from their knowledge of other infectious diseases caused by germs, such as the common cold (level 2). Participants who believed kissing was a possible route of HIV transmission used theories of casual contact or contagion, for example coming into contact with saliva or from physical contact. Finally, a few participants in the ND and PD group were also able to discuss how the environment in a swimming pool is not conducive to the survival of HIV and that chlorine will kill the virus.

7.7. Summary: Bringing the Data Together

This section will summarise the data from both the structured and semi-structured health questionnaires in an attempt to provide a more in-depth picture of young people's health knowledge and understanding.

The findings of the semi-structured interviews reflected to a large degree those reported in the quantitative section, with the ND group demonstrating the most sophisticated understanding about health, followed by the PD group and lastly the ID group, with group differences being most discernable in the area of sexual health. Additionally, using open-ended questions allowed an insight to be gained on how young people's health knowledge is organised and the types of misconceptions that lie behind their assumptions. Spontaneous answers are a better indication of the participants' salient beliefs around health issues than structured questionnaires and as such are more likely to reflect their actual application of knowledge. However, at the same time this does not mean it can be assumed that things which were unsaid are unknown by the participants and this should be kept in mind. In addition, answers to open-ended questions tend to be extremely variable between participants owing to factors such as confidence and levels of comfort discussing the health topics. Thus, a great deal of time was invested in developing measures to assess the young people's knowledge and understanding.

The fewest differences across groups were seen on the healthy eating questionnaires, with participants in general having a good grasp of what constituted a healthy and unhealthy

diet. However, young people were more aware of the health benefits of avoiding ‘unhealthy’ foods than they were of including ‘healthy’ foods in the diet. This was particularly evident for young people with ID, for whom eating healthily was largely defined as ‘not eating unhealthy foods’. Even when participants in the ID group discussed the importance of including foods they considered to be ‘good for you’ in the diet, they frequently referred to the absence of unhealthy qualities, as opposed to discussing any good qualities the food might have. This suggests that the participants with ID had rather a negative view of healthy eating, equating it with the restriction of food. Not only is this unlikely to motivate young people to adopt healthier habits, but focusing on avoiding foods can be problematic if it means some foods are omitted from the diet, but without the knowledge of how to replace them with healthier versions. It also seemed that the participants with ID held a ‘black and white’ view of healthy eating, where food can be good for ones’ health or it can be bad, what Rasnake et al. (2005) described as ‘categorical thinking’. Participants tended to look for one property of the food that was healthy or unhealthy, and classified it according to this, for example with meat and fish. Again, not only can this lead to deficiencies in key nutrients if entire food groups are being omitted from a diet, but this also makes it difficult for individuals to translate health messages into actual behaviour. Moreover, these findings highlight the need to be aware how people interpret health messages, particular for people with ID who may find the contradictory messages that surround healthy eating difficult to understand.

With regard to knowledge and understanding about alcohol, participants in the ID and PD groups tended to discuss fewer positive outcomes associated with drinking than did their non-disabled peers, which could relate to their more limited experiences with alcohol. Similarly, the structured questionnaires revealed that the majority of participants in the ID group believed that you had to be over 21 years of age to legally consume alcohol, once again suggesting that perhaps alcohol did not play a significant role in their lives. An interesting finding was that the PD group more strongly endorsed the possible health effects with drinking, including vomiting and loss of coordination than the ND or ID groups. This stronger endorsement of the negative outcomes of alcohol use again suggests that the participants with PD had negative attitudes toward alcohol use.

It has been suggested that as the health consequences associated with heavy drinking may occur many years in the drinker’s future, so these risks may not seem salient to adolescents

‘who think and act in a more immediate time frame’ (Mackinnon, 2007). This could account for why several participants in the ND group less strongly endorsed possible health outcomes associated with drinking.

Although participants were aware that drinking too much alcohol could be damaging to health, explanations of how alcohol caused this damage were more varied. Not surprisingly the ID group gave the least sophisticated explanations, however, even amongst the ND and PD groups, several participants had little understanding about the effects associated with heavy drinking. From a young age, children are exposed to many health messages about alcohol and nutrition, but this often takes the form of seemingly unconnected facts. The structured and semi-structured interviews revealed that participants had numerous facts about alcohol and healthy eating, yet for many this knowledge remained fragmented. Not only will this mean that such information is difficult to understand, but also is unlikely to translate well into actual behaviour (Au et al., 1999)

The largest differences in knowledge across groups were found in relation to sexual health. Both the structured and semi-structured questionnaires revealed that young people had misunderstandings around pregnancy and contraception, although these were most evident in the two disability groups. Whereas the structured questionnaire identified the myths participants had, the semi-structured interview provided insight into why participants had these misconceptions. Participants in the ID and PD groups were less knowledgeable about types of contraception, how to use them and how they worked to prevent pregnancy and/or HIV. Although this is perhaps unsurprising for the ID group as the sexual reproduction is a complex biological process, the finding that the PD group also shared similar misconceptions suggests that such knowledge is not being effectively targeted at these individuals. Not having an understanding of the biological process of reproduction made it difficult for participants in the ID and PD groups to reject the myths presented to them and to assess the relative risk of different behaviours. The aim of health education is to encourage young people to reason sensibly and independently. Although formal sex education is likely to be an important source for information on the biological aspects of sex, discussing sexual matters with friends and family may help to clarify misunderstandings or develop this understanding. Indeed, it has been reported that young people often viewed school sex education as ‘supplementary’ to more informal sources, with friends providing knowledge that focuses on skills, such as how to use a condom, how

to say no, and how to access free condoms (Buston and Wight, 2002). The finding that participants with disabilities in the present study lacked knowledge about more practical aspects of contraception, such as age restrictions and cost, may be reflective of these limited opportunities to discuss sexual matters with peers (Buston and Wight, 2002). Of course, it should be noted that several participants in the ND group also held misconceptions about sexuality.

Interestingly, although there were gender differences in participants' responses, these were most apparent in the ND group. For example, in the structured questionnaire, females more strongly endorsed the belief that pregnancy could happen the first time an individual has sexual intercourse or if the female has sex whilst she is menstruating. This might simply reflect women's greater fears about becoming pregnant.

With regard to HIV, all participants understood the risk of sharing needles and having unprotected sex, which corresponds with past research suggesting that these are the best known routes of HIV transmission (Sigelman et al., 1996). However, there were significant gaps in participant's ability to explain how HIV is transmitted, particularly in the ID and PD groups. For instance, although the majority of participants understood coming into contact with blood was potentially risky, it was mainly the ND group who discussed how blood has to be internalised for HIV transmission to occur (merely touching blood is not sufficient to cause infection). Having this biological knowledge of HIV then allowed ND participants to reject the myths they were presented with, including the myth that HIV can be transmitted through kissing or hugging, and with a more novel behaviour such as using the same swimming pool as someone who is HIV positive. In turn, being able to reason sensibly about risk will reduce the fear and anxiety that may surround HIV. For example, on the Likert-type scales, participants in the ND group did not perceive touching an open wound as risky, because they were aware that touching blood would not transmit HIV unless the recipient also had an open wound.

To be able to design educational interventions that are effective and appropriate to the individual, it is important to start by identifying their knowledge and information needs. Consequently, more effective methods for finding out about young people's understanding of health matters are required. Phase I of this thesis used several different methods to elicit young people with and without disabilities' health knowledge across a range of health topics. Multiple-choice questions, Likert-type scales, open questions and card sorting

activities were used to explore how knowledge is organised and also to identify participants' misunderstandings. Most research that has examined young people's health knowledge, particularly young people with disabilities, has tended to rely upon closed-question interviews with the aim of identifying levels of correct knowledge. However, equally important is to explore what young people do not understand. Even when young people demonstrate good knowledge about a given health topic, they can still harbour misinformation or misconceptions and education programmes also need to focus on the breaking down of these misconceptions. Holding incorrect beliefs may not only lead to fear and vulnerability, but it can also affect how correct information is understood and used.

The Next Phase

Intuitively if an individual is more knowledgeable about the benefits of engaging in healthy behaviours and avoiding health damaging behaviours then they will behave in ways that fit with these beliefs. Yet time and again, research has shown that the knowledge-behaviour relationship is not straightforward and understanding is often unrelated to the tendency to engage in risky health-related behaviours associated with sex, drugs and alcohol abuse (DiClemente, Hanson, and Ponton, 1996). Nevertheless, fewer opportunities for people with ID to discuss or learn about sexual matters can lead to more negative attitudes toward sex, which in turn may lead to lower levels of sexual expression (McCabe, 1999; Siebelink et al., 2006). This will be explored in the next phase of this thesis.

Chapter 8: Phase II Methodology

8.1 Introduction

The literature review revealed that young people often choose to engage in risky behaviours despite a sound knowledge of the health risks involved. Young people's health behaviours are frequently motivated, not by health but by the powerful currents in their lives, such as identity formation, developing and maintaining friendships and intimate relationships and establishment of autonomy. In fact, it may be the case that for the young person not to engage in a health risking-behaviour is actually perceived as more risky to their self-image than engaging in it. For example, Burtney and Duffy (2004) discuss how fears about being negatively evaluated for not knowing how to use a condom may lead to an individual engage in unsafe sex. However, to date very few studies have considered how young people with disabilities assign personal meanings to their experiences within health related situations or the outcomes they aim to achieve in these situations.

8.2 Aims and Objectives of Phase II

The overall aim of this research was to develop a deeper insight into the impact of key aspects of social exclusion - impoverished social networks and access to sources of health information - on young people's health knowledge, understanding and behaviour. In Phase I, participants' health knowledge and understanding were explored. Phase II is concerned with personal motivations for choosing to engage in health-risking behaviour. The aim was to recruit participants into the study who had also taken part in Phase I.

Phase II aimed to identify any differences between adolescents with and without disabilities in relation to their perceived social consequences of engaging in or refraining from potentially health-risking behaviours, relating to i) alcohol consumption and ii) sexual behaviour. The participants' emotional responses to these outcomes were also investigated. Differences in the social goals participants with and without disabilities wish to achieve in potentially-health risking situations were also explored.

The specific objectives of phase two were to explore whether there are differences between young people with (i) no disability, (ii) an intellectual disability and (iii) a physical disability, but no cognitive impairment, in the following areas:

1. Expected evaluations from unknown peers, close friends, parents for either engaging in or refraining from potentially health-risking behaviour. For the potentially risky sexual behaviour only, participants were asked about their expected evaluations from members of the opposite sex.
2. The value participants associate with these expected evaluations from each of the audiences (how much these evaluations matter to them).
3. Participants' salient goals within potentially health-risking situations
4. For the potentially risky sexual behaviour, gender differences in the above three areas.

8.3 Recruitment

Participants who had completed the Phase I health interviews were invited to take part in this second phase. As discussed in section 5.5, the non-disabled and intellectual disability groups were recruited from further education establishments throughout Glasgow. The physical disability group was recruited mainly from secondary schools in Glasgow. Of the 83 participants who had completed the Phase I interviews, 67 out of the 83 (80.7%) also went on to complete the Phase II interviews. Reasons for not completing both phases were that either the participant had left or moved college (*n*11) or declined to take part any further owing to other commitments (2) or not being interested (3). Further details on ethical considerations, recruitment, and research setting are provided in sections 5.4, 5.5 and 5.6., respectively. Figure 5.2 shows a flow chart for the recruitment of study participants.

8.4 Vignettes as a Research Methodology

One approach that is particularly appropriate for addressing the research aims is 'vignette methodology', a research tool previously used with young people and adolescents in the

area of health and, albeit to a lesser extent with people with ID. What follows below is a brief critique of the appropriateness of this method to the current study.

Vignettes can be described as short stories or simulations of real events that have been designed to depict a circumstance or specific issue (Finch, 1987; Flaskerud, 1979). These are then presented to participants to elicit their knowledge, beliefs and values on a given subject matter (Gould, 1996). They make reference to what are thought to be the most important factors in the judgment making process of participants. Although vignettes focus on specific variables, by systematically varying characteristics within the vignette they can produce data that is rich and studies that are methodologically sophisticated (Forrester, 1990; Forrester and Murphy, 1992).

Characteristically, research participants are presented with the vignette and asked to respond by stating what they would do in a given situation, or how they thought someone else would react. This can be done through responding to pre-determined or directed questions, using Likert or rating scales or using a more open-ended format. It is argued that this method illuminates thought processes, feelings and reactions in the participant, as he or she talks through their decision. Most commonly, vignettes are presented as written narratives, however they can take the form of text, images, music, film, art and photography (for a review see Hughes, 1998). They have been used within focus groups and with individual interviews, either as a self-contained method or in addition to other methods. Vignettes can be used at varying stages in the research process, such as hypothesis forming, piloting, ice-breakers, hypothesis testing and closing interviews (MacAuley, 1996; Sim et al., 1998; Wade, 1999).

Although using vignettes as a methodological tool in the social sciences dates back to the 1950's (Anderson and Anderson, 1951; Herskovits, 1950), Gould (1996) states that their growing popularity stems from a dissatisfaction with questionnaire-based studies of attitudes, beliefs and values, particularly in the area of health and illness. One criticism of questionnaire-based studies is that they are open to multiple interpretations by participants. With vignettes information can be standardised and as participants respond to the same stimuli the data produced is comparable across participants, thereby controlling for extraneous variables (Gould, 1996).

Vignettes have been used across a broad range of topics and contexts, including those of a personal or socially sensitive nature (Gott, Seymour et al., 2004; Hodgins, Millar and Barry, 2006; Link et al., 1999; McGlynn et al., 1976; Ouslander et al., 1993; Schwappach and Koeck, 2004; Stolte, 1994). They have also been used to explore health-related attitudes, behaviours and decision making in children and young people (Cameron, Stritzke and Durkin, 2003; Dalton, Bernhardt et al., 2005; Duryea and Okwumabua, 1985; Finkelstein and Brannick, 2000; Johnson and Johnson, 1996; Query et al., 1998; Wyvill and Ives, 2000). In relation to people with intellectual disabilities, vignettes have been used to explore capacity to provide informed consent to hypothetical treatment vignettes (Arsott, Dagnan and Kroese, 1999; Morris, Niederbuhl and Mahr, 1993), decision making behaviors (Hickson, Golden et al., 1998; Jenkinson and Nelms, 1994; Tymchuck, Yokota and Rahbar, 1990) and aggression (Jahoda et al., 2006; Pert and Jahoda, 2008; Pert et al., 1999).

Vignettes are useful in discussing topics that are socially sensitive and difficult to discuss (Finch, 1987; Gott, Seymour et al., 2004; Link et al., 1999). When researching alcohol use and sexually related behaviours a number of methodological challenges emerge. Young people are aware that these behaviours are subject to criticism from adults and this can lead to a tendency for responses to be more socially desirable and less likely to reflect their actual attitudes, beliefs and values (Embree and Whitehead, 1993). The occurrence of socially desirable responses is greater with adolescents and children, even when the anonymity of their responses is assured (Carifio, 1994). In addition, as discussed in the literature review, young people with ID tend to have lower levels of autonomy than their ND peers, which may lead to a tendency to give responses that fit in with their parents' or other adults views. Vignettes can help to distance participants from the topics being explored, making them less threatening (Finch, 1987; Hughes, 1998; Hughes and Huby, 2002). For example, McKeganey et al. (1996), in interviewing drug injectors about their borrowing and lending practices for drug injection equipment, found an increased reported preparedness to borrow when using vignette methodology than through self-report (7 percent versus 32 percent), suggesting a reduced tendency for socially desirable responses. On the other hand, these authors also acknowledge that for some participants, vignettes may be seen as an opportunity to 'flirt with risky behaviour at no personal cost' (McKeganey et al., 1995; p. 1259).

Vignette methodology is potentially valuable in working with young people, particularly those with intellectual disabilities, due to its 'story telling nature'. This helps to engage the participant and make the interview process more accessible and easier for the participant to follow (Kayser-Jones and Koenig, 1994). In turn this avoids the interview being perceived as a test-like situation which could promote a defensive mindset. This is of particular relevance for young people with ID who may have experienced failures in previous 'testing' situations. Finally, vignettes may encourage participants to compare their own experiences with the situation being described (Hughes, 1998), thereby encouraging them to reflect on their own situation (Finch, 1987).

Consequently, although the vignette methodology offers many advantages, there are a number of criticisms and drawbacks. One difficulty is that responses to hypothetical vignettes may not always reflect the actual behaviour and emotional involvement found in real-life situations (van Nieuwenhuijzen et al., 2005). In addition, vignettes depict a circumstance or specific issue, and therefore only certain aspects of life are selected. Therefore, vignettes cannot reflect the complex dynamics of people's lives (Hughes and Huby, 2002). Responses to hypothetical situations are also less spontaneous than in real life, with more time being available to process information and reflect on the possible response options (Orobio de Castro et al., 2002). Also lacking is the continuous interaction and feedback received in everyday situations (Hughes, 1998). The detachment and distancing that makes sensitive topics less threatening can also mean that vignettes are not comparable with real life (Hughes, 1998).

Therefore, although vignette methodologies may help to illuminate different factors involved in peoples' mental processes by providing a situated context in which to respond, they cannot mirror real life and all its complexities. Care must therefore be taken when attempting to generalise from a particular vignette scenario (Hughes, 1998). In reviewing past research, several principle guidelines for developing and using vignettes in research can be extracted, which may help to increase ecological validity; that is the degree responses to hypothetical situations reflect the behaviours that actually occur in natural settings. These are discussed below:

- i. Vignettes must be ecologically valid; they need to be both relevant and realistic for the sample population. Incongruities between the situation or characters in vignette and the participant's actual experiences will impact upon the participant's ability to imagine

themselves in the hypothetical situation (Swartzman and McDermid, 1993). This can be achieved through examining the existing literature, discussing scenarios with experts in the field, and most importantly conducting detailed pilot work with the target population (for example see Flaskerud, 1979; Gould, 1996).

- ii. The vignettes need to provide the participants with sufficient details about the context to ensure that they both understand the situation and that all participants are interpreting the situations in the same way. At the same time, vignettes need to remain vague enough to allow participants to interpret the situation in a way that reveals the nature of their decision-making and the different factors that they might place emphasis on (Hughes, 1998). If either the vignette and/or the questions pertaining to the hypothetical situations are too structured, there is the risk that participants will respond in a way that they may not have necessarily thought of themselves, thus increasing the distance between response and actual behaviour (van Nieuwenhuijzen et al., 2005)
- iii. In addition, careful development and piloting helps make certain the situation depicted in the vignette genuinely portrays the phenomenon of interest and that questions relating to the hypothetical situation are measuring the same phenomenon (internal validity; see Flaskerud, 1979).
- iv. Careful consideration needs to be given to the format of the vignette and this needs to be appropriate for the target population. For example, verbal difficulties will impact on the participants' ability to report the mental processes underlying their decision-making (van Nieuwenhuijzen et al., 2005). Visual stimuli to support verbal text may be appropriate for children and people with ID to help combat difficulties with memory and concentration, as well as comprehension.
- v. Vignettes need to be readily understood, keeping them as uncomplicated as possible. For example, Weisman and Brosigole (1994) found that although people with ID are as proficient at responding to short vignettes as people without disabilities, longer vignettes produced problems relating to concentration and increased error rates.
- vi. Standardised prompts should be developed prior to administering the vignettes to avoid difficulties with social desirability; where participants may initially say what they think

should happen and not what they think *would* happen. Probing responses can help to ensure the validity of responses (Hughes, 1998).

- vii. It has been suggested that situations depicted in vignettes should remain ‘mundane’, avoiding eccentric characters and disastrous events (Finch, 1987; Hughes, 1998), although others have argued that introducing controversial behaviours may be more engaging, in particular for children and young people (Hazel, 1995).
- viii. The generalisability of the data from outside of the hypothetical situation should be held in mind at all times, especially when analysing data (Hughes and Huby, 2002).
- ix. All materials, verbal and visual, should be carefully piloted.

8.5 Development and Piloting of the Vignettes

8.5.1 Development of the Vignettes

In phase I, young people’s knowledge and understanding about two ‘public’ health areas (healthy eating and alcohol consumption) and two ‘private’ health areas (contraception and HIV/AIDS) were investigated. These were themes were pursued in the second phase of the study. Therefore, young people’s expected outcomes for engaging in and refraining from an alcohol related situation and a sexually related situation were explored. The Social Goals and Strategies for Conflict (SGASC) assessment developed by Pert and Jahoda (2008) was used as a framework for the current study. As far as possible, the same individuals who took part in phase I were interviewed here, allowing data from the two phases to be compared and to capitalise on the rapport that had already been developed. As the social-cognitive processes being examined had not been explored previously in people with intellectual disabilities in the area of health, the development of the research questions and piloting of the materials represented a significant stage of the study. This was to ensure the ecological validity of the verbal and visual stimuli for use with people with and without a disability, as well as making the materials relevant and engaging. The initial steps in developing the research instrument and establishing its validity, which draw on the guidelines discussed earlier, are outlined in table 8.1. What follows below is an account of the changes made during this process.

Table 8.1: Key Steps in Developing the Research Instrument and Establishing the Validity of the Vignettes

Key Considerations and Aims	Action	Outcome
1. Establish the health areas to be explored	Predicted evaluations from others for engaging or refraining from a potentially risky (i) alcohol related behaviour and (ii) a sexually related behaviour	
2. Ensure vignettes appear plausible & real to participants	<p>Literature review to inform behaviours to be investigated and information to be included in the scenarios:</p> <ul style="list-style-type: none"> • Past research in the area of alcohol and sexual health. • Studies conducted with people with ID • Pilot work/information gained from Study I 	<p>Eight draft vignettes were developed:</p> <ul style="list-style-type: none"> • Four explored expected evaluations from others for accepting or refusing the offer of an alcoholic drink • Four explored expected evaluations from others for engaging in or refraining from a potentially risky sexually behaviour.
3. To assess the face & ecological validity of the assessment materials	<p>The vignettes were discussed with experts in the fields of Health Psychology and Intellectual Disabilities, including persons with published research using similar methodologies with people with ID. The following issues were addressed:</p> <p>Were the vignettes (i) appropriate for the research question(s) and (ii) relevant and realistic for participants, (iii) suitable for people with ID, (iv) was the structure of the questionnaire appropriate (including wording and vocabulary, response type, i.e. open-ended, forced choice, length etc.)</p>	<p>Appropriate modifications were made, and the vignettes were piloted with five young people with ID.</p>
4. To assess the suitability of the visual stimuli	<p>Each vignette was illustrated with colour photographs, as were the forced choice questions.</p> <p>Several photographs for each scenario were developed and shown to non-disabled individuals who were asked to give their general comments. The types of remarks ranged from how accurately the visual stimuli reflected the story/people's experiences and how the storyboard flowed, to the expressions on the characters faces and any potentially distracting or confusing information.</p> <p>A series of photographs were also developed for the forced choice responses.</p>	<p>Following appropriate modifications, the visual stimuli were piloted with five young people with ID. Participants were asked several questions about the photographs <i>prior</i> to hearing any of the stories (<i>i.e. can you tell me what you think is happening in this picture?</i>)</p> <p>The photographs for the forced choice responses were shown to ten people without disabilities who were asked to rank them in order of their ability to reflect the concept in question. They were also encouraged to make any comments on the stimuli.</p>
5. Piloting of Final Instrument	To assess the suitability of the entire instrument (both visual and verbal stimuli), in addition to its ability to elicit information required to answer the research questions, it was piloted with five young people with a range of abilities.	

8.5.2 Changes Influenced by Piloting

The aims of the piloting were to ensure the appropriateness and validity of the final instrument, some of which have been distilled from the literature on vignette methodology (see guidelines in section 8.4).

8.5.2.1 Do participants engage with the instrument?

Observations were made on how participants responded to the vignettes, both the verbal and visual elements. Following the suggestions of Hughes (1998) attention was paid to subtle indications that participants were engaging or ‘getting into’ the stories, for example whether participant’s tutted or shook their heads as the story unfolded, which was frequently observed. It was also noted that, in particular with the young people with ID, participants would frequently finish off the story before being informed of what happened next, which suggested that they were both interested in the stories and that they appeared real to the participants. Participants also stated that they enjoyed the interviews and the materials used.

8.5.2.2 Are the vignettes ecological valid?

Participants would often give more detail than was required, for instance talking about other characters in the scenario and about the events that may have happened beyond the given storyline. Although one has to be careful that participants do not get distracted with details irrelevant to the story, this did demonstrate that participants related to the stories and they reflected, to some extent, their own experiences.

The fact that participants drew on their own experiences to explain what they thought would happen in each vignette (for example, “*Well, when I’m in that situation I normally...*” or “*That happened to me once and I did...*”) indicated the vignettes were accurately reflecting participants’ experience. Participants also drew on their friends’ experience of such situations as well as on other sources, for instance television programmes (“*Yeah that happened on Eastenders the other day...*”). It is also worth noting that none of the young people whom the instrument was piloted with said that they could not imagine themselves in such a situation (illustrated by a non-response).

8.5.2.3 Is the level of detail in the vignettes appropriate?

During piloting participants requested further information about the situations that were not included in the photographs or the standardised text. For example, with the alcohol scenario, participants often wanted to know the exact amount they had drank before accepting another drink. It was decided that this would not be specified in the vignettes as people have difference tolerance levels and instead participants were asked to imagine *“you have had quite a few drinks”* and *“you begin to feel a bit drunk/dizzy”*. Standardised responses were then developed in case participants did require further information, and this was done for both scenarios. Standardised prompts were also used if no satisfactory answer was obtained for the open-ended questions. For example, upon asking *“What do you think the other people at the party would think about you if you left with the guy?”* if no response was given or if it was unclear, participants would be asked *“Do you think they would think good or bad things about you?”* The order the prompts were presented in (i.e. positive, negative) was alternated to prevent participants getting stuck in a particular response set.

The behaviour in the vignettes had to be seen as normative in order for them to elicit answers to the research questions; that is, it had to be clear that the participant was either conforming with the behaviours of others at the party or conflicting with their behaviour. From the pilot interviews it became clear that this was not obvious to the participants, who believed that they would be the only person engaging in the risky behaviour. Therefore it was made clear in the vignettes that other people were also drinking alcohol or leaving with members of the opposite sex at the party.

8.5.2.4 Is the structure appropriate?

The main change to the structure of the instrument as a result of piloting was that the number of scenarios used for each health behaviour was reduced. Initially, scenarios were developed that portrayed both a high and low risk behaviour, for example accepting one alcoholic drink (low risk) versus accepting a drink after several had already been consumed (high risk), and kissing a guy/girl (low risk) versus leaving the party with him/her (high risk). The resulting instrument was quite repetitive and time consuming and as the main aim was to explore the role of perceived evaluations for engaging in or refraining from health *risking* behaviours, only the high risk scenarios were kept.

Consideration was also given to the forced choice answers; these were designed to explore whether young people predicted a positive, negative or neutral evaluation from others for engaging in or refraining from the potentially risky behaviour. In the initial versions of the instrument, terms such as would others think you were '*cool*' or that you were '*boring*' were used. However as a result of piloting these seemed too specific and participants interpreted them in different ways. Therefore, the categories were kept broader, for example, '*would others talk to you more/like you more*' or '*would others ignore you/like you less*'. The order (positive, negative and neutral) was alternated throughout the interview to prevent participants getting stuck in a particular response set.

It was also noted that when participants had completed the alcohol scenarios and had moved onto the sexual health ones, they were still answering the questions as if alcohol was involved. Therefore the order of the vignettes (alcohol versus sexual health) was alternated so that half of the participants were read the alcohol vignettes first, and half the sexual health ones. However, even when this was done, people seemed to assume alcohol was involved at the party, even if it was not mentioned.

8.5.2.5 Is the format suitable?

Each vignette was illustrated with a series of colour photographs. A series of questions were asked of participants to ensure that the visual stimuli that were used to represent the vignettes were clear and accurately represented the storyline, (i.e., '*tell me what is happening in this picture?*' '*How do you think this woman/man feels?*') Piloting highlighted that participants were easily distracted by irrelevant details in the photographs (for example the activities of people in the background) and these were amended accordingly. Other photos failed to represent the events occurring within the scenario and new photos were taken in light of the comments made by participants.

8.5.2.6 Are there issues of social desirability?

Another important consideration was that participants were answering honestly; that is they were saying what they genuinely thought *would* happen not what *should* happen. It was noted that when asked about their own social goals (i.e. what they would do in a particular situation) participants sometimes stated what they thought should happen as opposed to what they would have chosen to do themselves. Following the advice of

Hughes (1998), further prompts were introduced so that the first response given was not taken at face value. The responses participants gave did appear open and honest, suggesting that on the whole they were not giving socially desirable answers. To allow internal reliability checks, answers were compared across the two vignettes to ensure participants were reasonably consistent.

8.5.2.7 Conclusion

Overall, owing to a thorough literature review of previous studies and research methodologies, in addition to discussions with experts in this area, the methods developed were generally well received by participants. Following piloting and subsequent modifications, it was confidently believed that the validity of the instrument has been established. The final instrument was then administered to a further five participants with ID and no further changes were made to the instrument.

A copy of the vignettes and associated visual stimuli can be found in Appendix G.

8.5.3 Final Materials Developed from Piloting

Four vignettes depicting a hypothetical situation where the participant attends a party were used as a basis for questions regarding the expected outcomes of (i) an alcohol related behaviour (a character in the story offers the participant a drink of alcohol) and (ii) an action that could lead to a potentially risky sexually behaviour (a character in the story asks the participant to leave the party with them). Participants were read the story and asked to imagine him or herself either agreeing to engage in the risky behaviour or refraining from it.

To ensure that the visual cues were similar across all vignettes, the only difference between the alcohol and sexual health scenarios was that there was no alcohol present in the latter scenario. Whether the participant engaged in or refrained from the specified behaviour was the only difference within each subset of vignettes. To aid understanding of the hypothetical vignettes, a series of five photographs were taken to depict each of the stories. Two versions of each vignette were drawn up, one for males and one for females. For alcohol related behaviour, participants were asked to imagine a person of the same-sex offering them a drink. This helped avoid responses being influenced by gender stereotypes

(e.g. “men try to get women drunk”). For the potentially risky sexually behaviour a member of the opposite sex was depicted as asking the participant to leave the party. In this way, the current research instrument only explored heterosexual relationships.

8.5.3.1 Alcohol Related Vignettes

Predicted Outcomes for Accepting Alcohol: To investigate the participants’ predicted outcomes of accepting an alcoholic drink they were presented with the vignette, illustrated by five colour photographs shown at the same time (appendix G). Participants were presented with a vignette in which they had been invited to a party by a friend:

Your friend is going to a party of some people he/she knows. Your friend invites you to go with them. You don’t know anyone else who is going, but you decide to go to the party. When you get to the party there are lots of people your age (*photograph of a group of young people drinking and socialising*). They are drinking alcohol and are having a good time.

Imagine that you have been at the party for a while and you have had quite a few drinks (*photograph of a selection of different alcoholic beverages*). You begin to feel a bit drunk/dizzy. Other people at the party are quite drunk as well. You start talking to a group of people at the party (*photograph of three young people drinking alcohol*). One of the people in the group offers you another drink (*photograph of a male/female character offering a drink*).

Imagine that you **TAKE** the drink (*photograph of drink*)

A series of questions were then asked about the expected responses of (i) the other people at the party (unknown peers), (ii) their parents (authority approval) and (iii) their friends (close peers). The first questions were open, for example “*What do you think the other people at the party would think about you when you accepted the drink?*” For the Unknown Peers and Close Peers categories, forced choice questions were then asked regarding whether the expected response would be (i) positive (“*When you took the drink, do you think the other people at the party would think more of you / like you more?*”) (ii) negative (“*When you took the drink, do you think the other people at the party would think less of you/ignore you?*”) or (iii) neutral (“*When you took the drink, do you think the other people at the party would not be bothered?*”) For the expected parental response, forced choice questions asked whether participants thought their parents would think (i) they did the *right thing*, (ii) the *wrong thing* or (iii) would *not be bothered*. The order of the forced choice questions were systematically varied in order to ensure that there was no recency effect for items presented last.

Not all responses to the open-ended question referred to a predicted evaluation of the participant (e.g. *‘they would think I was mature’*), but referred to a general statement or evaluation of the situation/behaviour (*‘drinking is wrong’*), even with further prompting. Therefore, following the open-ended question with a forced choice question ensured that all participants were able to state how they expected others would evaluate them for engaging in or refraining from the behaviour.

Immediately following the presentation of each of the forced choice questions, participants were asked to rate how much this response would matter to them. Participants were asked to choose one of three options *“a lot / a bit / not at all.”* Throughout the assessment prompts and follow-up questions were used. For example, if someone said they would not care what their close friends thought about them, this was probed further to ensure that this is how they actually felt as opposed to the participant adopting a defensive stance.

Predicted Outcomes for Refusing Alcohol: The procedure and visual stimuli were the same as for the vignette where participants accepted the drink. However, participants were asked to imagine that they refused the offer of a drink:

Imagine that you say **NO** you don’t want the drink (*photograph of an outstretched hand, palm outward facing*).

Social Goals Associated with Alcohol-Related Behaviour: In order to elicit participants’ salient goals within these situations, participants were asked to say what they would do in this situation and then asked *why* they would act in that way. To help avoid social desirability in responses, participants were asked to imagine that they were completely free to decide what they did and to imagine that their friends or family would never find out. The visual stimuli described above were left in front of the participant; the final photograph illustrating whether they accepted the drink or refused was removed.

8.5.3.2 Sexual Health Vignettes

Predicted Outcomes for Engaging in Sexually Related Behaviour: The procedure was the same as described for the alcohol section, with the vignette being read out to the participant illustrated by four colour photographs shown at the same time (appendix G):

Your friend is going to a party of some people he/she knows. Your friend invites you to go with them. You don’t know anyone else who is going, but you decide to go to the party. When

you get to the party there are lots of people your age (*photograph of a group of young people drinking and socialising*). They are chatting to each other and having a good time. Some of the guys and girls are kissing (*photograph of a couple kissing*). You start chatting to this guy/girl you have not met before (*photograph of young male/female character*).

Some of the couples begin to leave together (*photograph of a couple leaving the party together, holding hands*). You have been chatting to him/her all evening. The guy/girl asks if you will go back to their house so the two of you can be alone. You have never been back to his/her house before.

Imagine that you say **YES** and leave with the guy/girl (*photograph of holding hands*).

The same open-ended and forced choice questions were then asked as described for the alcohol related behaviour, exploring the anticipated responses from unknown peers, parents and close peers, and also for this section, the expected reaction of the potential partner. Immediately following the presentation of the forced choice questions, participants were asked to rate how much this response would matter to them. Participants were asked to choose one of three options “*a lot / a bit / not at all*”.

Predicted Outcomes for Refusing to leave with the Character: The procedure and visual stimuli were the same as for the vignette where participants imagined they left with the character, but this time participants were asked to imagine that they refused to leave the party with the character:

Imagine you say **NO** and do not leave with the guy/girl (*photograph of an outstretched hand, palm outward facing*).

Social Goals Associated with Potentially Risky Sexual Behaviour: Following the presentation of the two vignettes, participants were asked to say what they would do in this situation and then asked *why* they would act in that way. The visual stimuli were left in front of the participant, except for the final photograph illustrating whether they left with the character or not.

8.5.4 Coding and Analysis of Responses

The interviews were recorded using a SonyTM ICD-MS525 digital recorder and transcribed verbatim, comments and observations that had been written down during the interview were also kept. The interviews lasted, on average, for 27 minutes and ranged from 16 minutes to 39 minutes. Participants’ identities were protected because all of the

participants and classmates, tutors or family members to whom they referred were assigned pseudonyms. In addition, place names were omitted from the transcripts (see section 5.4.2).

Table 8.2: Coding Categories for Open-Ended Response

Response	Description
Don't Know; No Response	Unable to respond, e.g. "I don't know what they would think".
Neutral	Indicates that the audience would not be bothered if the participant engaged in / refrained from the behaviour, e.g. "They wouldn't think anything"; "They wouldn't care".
Non-Specific Positive or Non-Specific Negative	Response is positive or negative, but does not reflect an evaluation of the participant; comment is made about the situation, e.g. "It's wrong to do that"; "They'd be glad you were safe".
Positive Evaluation or Negative Evaluation	Response reflects a positive or negative evaluation of the participant, e.g. "That I am a social person"; "They would laugh and talk about me".

Responses given to the open-ended questions about the expected outcomes of engaging or refraining in a potentially health risking behaviour were entered into NUD*IST. Responses were coded as either a positive or negative evaluation, or neutral response. Some participants, even after prompting, were unable to respond or gave only a general response about the situation (e.g. "*It's wrong of people to offer you a drink, they shouldn't do that*", or "*it's very dangerous to be in that situation*"). These responses were coded as either non-specific positive or non-specific negative (table 8.2). Several participants recognised that the anticipated reactions from people could be both positive and negative. These participants were asked to say which they thought was more likely and it was this response that was coded and used in the main analysis. Responses were then analysed using content analysis (see section 5.10.5), with positive, negative and neutral responses being grouped under broad headings such as 'sociable', 'responsible', 'boring' or 'angry'. As neutral responses all referred to how the other person would not be bothered or would not mind if they engaged in or refrained from the behaviour, these are not discussed further. However, these responses are reflected in forced-choice responses.

Data for the forced-choice questions, including the social goals data, were inputted into SPSS version 15.0 and are presented in chapter 9 of this thesis. As the data was non-parametric, Chi-square tests were used to compare the frequencies of each response across the three groups. In order to explore where the actual differences lay between the three

groups, the standardised residuals in each cell were examined and any trends discussed. As the numbers of responses in each category were relatively small, analysing the data for gender differences would have been difficult and important trends overlooked. However, it is acknowledged that this is an important area for further research using a larger sample to examine any gender differences across attitudes toward alcohol-related behaviour. For the sexual health scenarios, although the same dilemma applies, research has shown gender differences in attitudes toward sexual behaviour to be fairly robust (Oliver and Hyde, 1993). Consequently, as responses could be expected to differ for male and female participants, gender differences were explored. However, owing to the small numbers, this was descriptive.

To give a descriptive overview of the significance participants attached to the expected reactions (*'not matter at all / matter a bit / matter a lot'*), a series of detailed tree diagrams were created and these are presented in appendix H, with the probability scores derived from these being presented in the main text. Owing to the small numbers of responses in each category, the categories of 'not matter at all' and 'matter a bit' were combined into one category, of 'matter a little bit'. In addition, no formal statistics were performed here as the numbers were too small. For each group, the probability of each response occurring (the valence of response – negative/positive/neutral - and the value associated with this) was calculated in three stages. First, the number of participants giving either a positive, negative or neutral response was divided by the total number of participants in each group. Secondly, the significance that participants attached to their response was calculated; the number of participants stating that it would 'matter a lot' or 'a little' was divided by the total number of participants giving either a positive, negative or neutral response. These two scores were then multiplied to give an overall probability of each response occurring.

8.5.5 Methodological Rigour

Inter-rater agreements for coding the forced-choice and open-responses were calculated using Cohen's kappa (Cohen, 1960). Cohen's kappa determines the percentage agreement between two coders and then corrects that percentage for chance agreement. A second-rater was provided with a written description of the key characteristics of each category and randomly assigned twelve transcripts to code. Any discrepancies identified were discussed until agreement had been reached with the code allocation or with modifications

to existing codes. Cohen's kappa yielded reliability coefficients ranging from 0.63 to 0.93, with kappa values of 0.61-0.80 indicating good agreement, and kappa values of 0.81-1.0 very good agreement:

Cohen's kappa	Alcohol scenarios	Sexual behaviour scenarios
Open-ended responses:	0.84	0.81
Forced-choice questions:	0.93	0.92
Social Goals:	1	0.63

Although it appears there is low agreement for the sexual behaviour social goals, this was due to the small number of transcripts for which interrater reliability was conducted. In actuality, there was only one transcript that the two coders disagreed upon and after discussing this, agreement was reached.

8.6 Procedure

Interviews were arranged for participants who consented to the study via their teachers/lecturers. All participants were interviewed within the school/college. Before the interview commenced, the purpose of the interview was explained to the interviewees and they were encouraged to ask questions if they were unsure about the interview process. To avoid issues of social desirability when discussing behaviours that may be criticised by others, in particular adults, participants were encouraged to speak openly, were informed there were no right or wrong answers, and it was emphasised that it was their views and opinions that were important. Participants were assured that all answers given would remain confidential. The instrument was administered verbally to participants on an individual basis and in a quiet, undisturbed room. Half of the participants responded to the vignette depicting the alcohol related behaviour first and half the vignette depicting the sexually related behaviour. This was equally distributed for males and females. For participants who had not completed the Phase I interviews, the Wechsler Abbreviated Scale of Intelligence (WASI) was administered to assess intellectual functioning at the end of the interview. As discussed in section 5.4., at the end of the interview several minutes were spent debriefing the interviewee to ensure that s/he had not experienced any harm answering the questions and asked participants if they would like to add any further comments.

Chapter 9: Phase II - Expected Evaluations and Social Goals

9.1 Introduction

The aims and objectives of the study were outlined in the previous chapter and this chapter will focus on young people's expected evaluations for engaging in or refraining from potentially health risking situations, as well as their feelings regarding these evaluations and their social goals. After providing descriptive information about the participants who completed this phase, results are presented in two sections exploring participant's expected evaluations for engaging in or refraining from i) an alcohol related hypothetical situation and ii) a hypothetical situation that could lead to a potentially risky sexually behaviour.

9.2 Participants' Demographic Characteristics

Ninety-eight young people aged from 16-25 participated in the second phase of the study, of which 34 had no known disability, 34 had a mild/moderate intellectual disability and 30 had a physical disability. Of these participants, 22 (70%), 24 (82%) and 21 (91%) of the ND, ID and PD groups, respectively, had also participated in phase I of the study (see figure 5.2 for a flow chart for the recruitment of study participants). Participants' demographic characteristics for the three groups are displayed in table 9.1 As the majority of participants took part in both phases of the study, group differences in IQ scores (as measured by the WASI), Age and SES followed the same pattern as described in section 7.2.1. The non-disabled group had the highest IQ score (median = 97), followed by the physically disabled group (median = 96; adjusted by one standard error of measurement, see section 7.2.1), with the intellectually disabled group scoring the lowest (median = 61). Differences between the three groups were significant ($\chi^2 (2) = 66.320$; $p = 0.001$), this being due to the ID group having a lower score than the ND group ($z = -7.131$; $p=0.001$) and the PD group ($z = -6.908$; $p=0.001$). There were no significant differences between the ND and PD groups ($z = -0.404$; $p=0.7$).

Groups also differed by age ($\chi^2 (2) = 66.320$; $p = 0.001$). The physically disabled group had a medium age of 17 and were significantly younger than both the non-disabled group

(median age of 18; $z = -4.452$; $p=0.001$) and the intellectually disabled group (median age of 18; $\chi^2 (2) = -4.922$; $p=0.001$).

The sample was predominately deprived with 55.8% of the ND group and 50% of the ID and PD groups living in DEPCAT 5, 6 or 7 (table 9.1). There were no significant differences in SES across groups ($\chi^2 (2) = 1.38$, $p = 0.93$). All but one male participant with ID was living in the family home.

Table 9.1: Participants' Demographic Characteristics

	No Disability	Intellectual Disability	Physically Disability	
	<i>n</i> 34	<i>n</i> 34	<i>n</i> 30	
Male : Female	<i>n</i> 16 : 18	<i>n</i> 17 : 17	<i>n</i> 15 : 15	
IQ Scores			Unadjusted Score	Adjusted Score
Mean	96.7 ^a	61.2 ^b	93.2 ^c	96.2 ^{a†}
Median	97	56.5	93	96
Range	84-107	55-78	79-105	82-108
SD	5.2	8.5	6.4	6.2
Age				
Mean	18.71 ^a	18.38 ^a	16.87 ^b	
Median	18	18	17	
Range	16-25	16-22	16-19	
SD	2.1	1.13	0.9	
SES				
Mean	4.59 ^a	4.62 ^a	4.43 ^a	
% 1-2 (Affluent)	23.5	17.6	16.7	
3-4	20.6	32.3	33.4	
5-7 (Deprived)	55.8	50	50	

Means that do not share a superscript in common are significantly different from each other.

SES: socio-economic status; † These scores have been adjusted by two standard errors of measurement (section 7.2.1).

9.3 Expected Evaluations and Social Goals

For both the alcohol and sexual behaviour vignettes, the questionnaire consisted of three main sections; expected evaluations for agreeing to engage in the behaviour, expected evaluations for refraining from the behaviour, and salient social goals. After being presented with the vignette, participants were first asked the open-ended question about their expected evaluations and this was followed by the forced choice questions as described in section 8.3.3. However, in the following sections data are presented from the forced-choice questions first, followed by the open-ended responses. The reason for

changing the order of the presentation is that the forced-choice responses provide an overview of the number of participants in each group who predicted a positive, negative or neutral evaluation. The open-ended questions then provide insight into the types or evaluations or reactions participants expected.

9.3.1 Section 1: Alcohol Related Behaviour

9.3.1.1 Expected Evaluations for Accepting Alcohol

Forced-choice responses and value placed on evaluations: Table 9.2 shows that there were group differences in young people's expected evaluations from each of the audience groups (unknown peers, close friends and parents) when asked to imagine that they accepted the drink. With regard to value placed on associations, probability tree diagrams were created for each audience category in order to illustrate the value placed on expected outcomes (see section 8.5.4). These are presented in appendix H and the probability scores derived from these are displayed in table 9.3

Unknown Peers: The majority of participants in the ID group expected their *unknown peers* to evaluate them negatively for taking the drink, whereas most of the participants in the ND and PD groups expected a positive evaluation. In addition, table 9.3. shows that such evaluations mattered more to participants in the ID group than the other two groups.

Close Friends: With regard to *close friends*, table 9.2. shows that significantly more of the ID and PD groups predicted a negative evaluation compared to the ND group, who in turn more frequently stated their friends would not be bothered if they took the drink. With regard to how much these evaluations mattered to participants, responses were distributed fairly equally across groups, with approximately half of each group stating that what their *close friends* thought of them mattered a lot (table 9.3).

Parental Approval: Table 9.2 shows that most participants in each group anticipated *parental disapproval* for taking the drink, although more participants in the ND group stated their parents would not be bothered. The majority of participants in the ID and PD groups stated that their parents' views mattered a great deal to them (table 9.3).

Table 9.2 Expected Evaluations for Accepting the Drink – Forced-Choice Questions

		No Disability	Intellectual Disability	Physically Disability	
		<i>n</i> 34	<i>n</i> 34	<i>n</i> 30	
Unknown Peers	Positive	18	6	17	$\chi^2 = 13.4^{**}$
	Negative	11	22	9	
	Neutral	5	6	4	
Close Friends	Positive	6	6	6	$\chi^2 = 11.5^*$
	Negative	9	20	17	
	Neutral	19	8	7	
Parents	Positive	0	0	0	$\chi^2 = 7.5^{**}$
	Negative	23	29	28	
	Neutral	11	5	2	

*p = 0.01; **p = 0.01

Table 9.3 Values Associated with Expected Evaluations for Accepting the Drink – Forced-Choice Questions*

		No Disability		Intellectual Disability		Physically Disability	
		<i>n</i> 34		<i>n</i> 34		<i>n</i> 30	
		A Lot	A Little	A Lot	A Little	A Lot	A Little
Unknown Peers	Positive	.12	.41	.15	.03	.17	.40
	Negative	.15	.18	.29	.35	.13	.17
	Neutral	.06	.09	.12	.06	.07	.07
Close Friends	Positive	.12	.06	.12	.06	.10	.10
	Negative	.15	.12	.32	.26	.30	.27
	Neutral	.29	.26	.12	.12	.13	.1
Parents	Positive	0	0	0	0	0	0
	Negative	.24	.44	.71	.15	.77	.17
	Neutral	.09	.24	.06	.09	.03	.03

* Refer to appendix H for detailed Tree Diagrams

Open-Ended Response: Table 9.4. shows that with regard to the expectation of a positive evaluation, the majority of responses referred to the participant being seen as fun or sociable by *unknown peers* and *close friends* although this was cited more frequently by participants from the ND and PD groups. The majority of the predicted negative responses came from the ID group, who believed that others would (i) think the participant had a problem with alcohol, (ii) laugh and talk about the participant, or (iii) think the participant was irresponsible and foolish. These beliefs were also shared by a few of the ND and PD

participants. A small number of young people from the ND group acknowledged that in accepting the offer of the drink the participant would be perceived as conforming to the norm, yet this was viewed unfavourably.

Table 9.4: Expected Evaluations for Accepting the Drink – Open-Ended Questions¹

		ND	ID	PD	Illustrative Quote
Unknown Peer	Negative Non-Evaluation	--	3	--	"A bit worried that you might faint" ID, Female, 19
	Positive Evaluation				
	Negative Evaluation				
Close Friends	Negative Non-Evaluation	--	2	3	"Don't drink off a stranger" ID, Male, 17
	Positive Evaluation				
	Negative Evaluation				
Parents	Negative Non-Evaluation	--	4	6	"Ask what is was and not to do it again, watch how much you drink" ID, Female, 18
	Negative Evaluation				

¹Counts do not add up to group totals as neutral responses are not included in the table (see section 8.5.3).

The majority of participants expected their *parent(s)* to either be disappointed or angry with them, or to think they had acted irresponsibly. Interestingly, there were different views expressed by the three groups. While the ID and PD groups expected that their parents would be ‘angry’, participants from the ND group more frequently discussed their parents’ ‘disappointment’.

9.3.1.2 Expected Evaluations for Refusing Alcohol

Forced-choice responses and value placed on evaluations: Table 9.5. shows that when questioned about their expected evaluations for refusing the offer of the drink, the majority of participants predicted a negative evaluation from *unknown peers* and a positive evaluation from their *parent(s)*. Responses were more varied when predicting how *close friends* would evaluate them, although group differences were minimal and table 9.5. shows that none were significant.

The majority of participants in the ND group said it would not matter to them if the *unknown peers* thought either positively or negatively about them for refusing the drink, compared to approximately a third of the ID (table 9.6). The majority of participants across groups stated it mattered a lot to them what their *close friends* thought. The majority of participants in the ID and PD groups stated that their parents’ views mattered a great deal to them as did just under half of the ND group.

Table 9.5: Expected Evaluations for Refusing the Drink- Forced-Choice Questions

		No Disability	Intellectual Disability	Physically Disability	
		<i>n</i> 34	<i>n</i> 34	<i>n</i> 30	
Unknown Peers	Positive	6	8	3	$\chi^2 = 6.69$; ns
	Negative	27	23	21	
	Neutral	1	3	6	
Close Friends	Positive	9	13	15	$\chi^2 = 4.95$; ns
	Negative	6	7	6	
	Neutral	19	14	9	
Parents	Positive	29	33	29	†
	Negative	0	0	0	
	Neutral	5	1	1	

ns = not significant at 0.05 level. †As more than 20% of the response categories in the data set contained less than the expected frequency, Chi-square could not be computed

Table 9.6: Values Associated with Expected Evaluations for Refusing the Drink – Forced-Choice Questions

		No Disability		Intellectual Disability		Physically Disability	
		<i>n</i> 34		<i>n</i> 34		<i>n</i> 30	
		A Lot	A Little	A Lot	A Little	A Lot	A Little
Unknown Peers	Positive	.06	.12	.09	.15	.03	.07
	Negative	.06	.74	.21	.47	.2	.5
	Neutral	0	.03	.03	.06	.07	.13
Close Friends	Positive	.24	.03	.32	.06	.4	.1
	Negative	.12	.06	.21	0	.13	.07
	Neutral	.35	.21	.24	.18	.2	.1
Parents	Positive	.38	.47	.79	.18	.73	.23
	Negative	0	0	0	0	0	0
	Neutral	.06	.09	0	.03	0	.03

Open-Ended Responses: Table 9.7. shows that the few participants who predicted a positive evaluation from *unknown peers* at the party and *close friends* stated these other individuals would be proud of or admire them for refusing the drink and acting sensibly/responsibly, or that their *close friends* would just think they were having fun. The majority of participants who predicted a negative evaluation from their *unknown peers* discussed being perceived as antisocial, not being part of the group, or being boring. Other expected evaluations from *unknown peers* and *close friends* were being seen as scared of or not being able to handle alcohol or that refusing the drink would cause others to laugh and talk about them. With regard to expected evaluations from *parents*, all participants referred to how their parents would be happy and proud of them for making a responsible choice.

A number of participants in the ND and PD groups gave more than one response to the open-ended question and as discussed previously, participants were prompted to give the response they thought most likely (section 8.5.4). These participants discussed how behaviours can have both positive and negative connotations, and that evaluations of behaviour can change depending upon the context. For example, an individual may be viewed as fun and sociable by some, and as foolish and irresponsible by others. A few participants from the ND group also stated that the way one is evaluated is dependent on gender, for example alcohol being more acceptable for males.

Table 9.7: Expected Evaluations for Refusing the Drink- Open-Ended Questions¹

		ND	ID	PD	Illustrative Quote
Unknown Peer	Negative Non-Evaluation	1	3	8	"She's had enough, we'll take her home" ID, Female, 19
	Positive Evaluation				
	'Proud of you/ Admiration'	6	8	3	"Bit responsible, quite a nice guy. Know how far you can go", PD, Male, 16
	Negative Evaluation				
	'Antisocial/boring'	16	10	6	"Not very sociable, a bit restrained and quiet" ID, Female 21
Close Friends	'You're scared'	5	7	5	"That you're a wimp 'cos you can't take your drink like the others can", ID, Female, 19
	'Can't handle it'				
	'Others would talk/laugh'	1	6	5	"Laugh at you, call you names, slag you", PD, Male, 16
	Positive Non-Evaluation	--	4	2	"Happy" ID, Female, 20
	Positive Evaluation				
	'Proud of you/ Admiration'	7	9	10	"Responsible, they don't need to look out for you all the time", ND, Male, 17
	'Fun'	2	3	5	"I was trying to have fun, I was fun", ID, Male, 22
	Negative Evaluation				
Parents	'Antisocial/boring'	2	4	2	"They might...basically you're not a good laugh" PD, Male, 17
	'You're scared'	1	1	--	"Think you're scared" ID, Male, 17
	'Can't handle it'				
	'Others would talk/laugh'	1	2	3	"Some might talk behind your back" ID, Male, 19
	Positive Non-Evaluation	7	20	7	"Be very glad that I was safe" ID, Female, 18
Parents	Positive Evaluation				
	'Proud of you/ Admiration'	22	13	20	"Be proud of me, the sensible thing to do", ND, Female, 18

¹Counts do not add up to group totals as neutral responses are not included in the table (see section 8.5.3).

9.3.1.3 Social Goals Associated with Alcohol-Related Behaviour

In this section participants' salient social goals (what they would choose to do in the hypothetical situation and why) are compared across groups. Table 9.8. shows there were group differences in whether participants said they would accept or refuse the drink in the hypothetical situation. Participants in the ID and PD groups were more likely to state that they would not accept the drink compared to the ND group, for whom an equal number said they would accept the drink as would refuse it. The majority of participants in the ND and PD groups who reported that they would accept the drink said they would do so either

to promote a positive or avoid a negative evaluation from others. For example they would drink in order to appear more sociable and fun, or to avoid being rejected or laughed at by the group. Such a view was not articulated by any participant in the ID group; the three participants who said they would accept the drink did so in order to achieve non-specific positive outcomes, for example because they liked to drink.

Table 9.8. Social Goals for Accepting or Refusing the Offer of a Drink

		ND	ID	PD	Illustrative Quote
Would accept the drink*		17	3	9	
Promote Positive Evaluation	<i>Non-Evaluation</i>	2	3	--	<i>"If I felt like it" ID, Male, 18</i>
	'Sociable'	5	--	2	<i>"Makes you more sociable, outgoing, lose inhibitions. Seen as more up for a laugh, socially better with people" ND, Female, 21</i>
	'Fun'	7	--	1	<i>"I would probably just keep on, party on! I'm having a good time" ND, Female, 18</i>
Avoid Negative Evaluation	'To avoid rejection'	3	--	4	<i>"Probably would if in good mood and nice people... so to not feel different from others, to fit in with the rest of them", PD, Male, 17</i>
	'Others would talk/laugh'	--	--	2	<i>"Take it but don't drink it. I'd give someone else it because they would laugh at you", PD, Male, 16</i>
Would refuse the drink*		17	31	21	
Non-Evaluation	'Don't like alcohol' 'not allowed'	0	0	3	<i>"I don't like the taste" PD, Female, 18</i>
	'Safety'	7	7	9	<i>"I'd go home, wouldn't take another one, you'd get seriously ill" ID, Female, 18</i>
	'Intoxication'	4	22	6	<i>"Probably say no or eat something. It absorbs alcohol like a sponge. I don't want to be too drunk" ID, Female, 18</i>
Avoid Negative Evaluation	'Embarrassed'	3	--	2	<i>"Because wouldn't want to get to messed up, make a fool of self or fall out with people" PD, Male, 17</i>
	'Irresponsible'	3	1	1	<i>"I would worry they'd think I didn't care, that I was irresponsible" ND, Female, 17</i>
	Parental reaction	--	1	--	<i>"I wouldn't 'cos of my parents, what they'd think of me" ID, Male, 19</i>

* $\chi^2 = 13.7$; $p = .01$

The majority of reasons cited by young people across groups for *not* accepting the drink made reference to issues of safety and already being intoxicated. A further three participants from the PD group cited non-specific negative reasons for not taking the drink,

which referred to not liking the taste, not liking ‘the idea’ of drinking, and one participant stated he was not allowed to drink. A small number of participants said they would not take the drink to avoid a negative evaluation from others that may arise from acting in an embarrassing or irresponsible way. One participant in the ID group said she would not take the drink to avoid her parents thinking negatively about her.

With regard to how participants would feel if they followed the behaviour through, the majority of participants across groups stated that they would not be bothered or would feel positive about their choice. One male participant in the ND group and one in the ID group stated they would accept the drink, yet this would cause them to feel disappointed in themselves and guilty. A female from the ID group said she would refuse the drink, however she would feel miserable for doing so.

9.3.2 Section 2: Potentially Risky Sexual Behaviour

9.3.2.1 Expected Evaluations for Leaving with the Character

Forced-choice responses and value placed on evaluations: Table 9.9. shows that group differences were minimal in participants’ expected evaluations from unknown peers, close friends and parents when asked to imagine that they left with the character. The exception was for the expected evaluation from the *potential partner*, for which the ND group predicted more negative reactions. However, upon further examination of the data it became clear that there were significant gender differences in responses across groups.

Unknown Peers and Close Friends: More males than females in each group predicted that *unknown peers* and *close friends* would think positively of them for leaving with the character in the vignette. Most females expected to be seen negatively by peers and friends, although differences were most marked for the ND group.

There were few group differences with regard to the importance participants attached to these evaluations (table 9.10). The majority of males stated that evaluations made by *unknown peers* would not matter to them, compared to approximately half of the female participants. With regard to *close friends*, approximately half of the males in each group stated it mattered a lot what their friends thought about them, as did the majority of female participants across groups.

Table 9.9: Expected Evaluations for Leaving with the Character – Forced-Choice Questions

		No Disability	Intellectual Disability	Physically Disability	
		<i>n</i> 34	<i>n</i> 34	<i>n</i> 30	
Unknown Peers	Positive	12	6	6	$\chi^2 = 7.05$; ns
	male: female	12 : 0	5 : 1	6 : 0	
	Negative	20	19	17	
	male: female	2 : 18	6 : 13	3 : 14	
	Neutral	2	9	7	
	male: female	2 : 0	6 : 3	6 : 1	
Close Friends	Positive	9	9	5	$\chi^2 = 3.66$; ns
	male: female	9 : 0	7 : 2	5 : 0	
	Negative	16	20	21	
	male: female	2 : 14	8 : 12	8 : 13	
	Neutral	9	5	4	
	male: female	5 : 4	2 : 3	2 : 2	
Parents	Positive	0	0	0	$\chi^2 = 5.81$; ns
	Negative	26	28	25	
	male: female	8 : 18	13 : 17	10 : 15	
	Neutral	8	6	5	
	male: female	8 : 0	4 : 0	5 : 0	
Potential Partner	Positive	15	20	24	$\chi^2 = 17.3^{**}$
	male: female	11 : 4	10 : 10	14 : 10	
	Negative	15	5	2	
	male: female	1 : 14	4 : 1	0 : 2	
	Neutral	4	9	4	
	male: female	4 : 0	3 : 6	1 : 3	

* $p = .01$; ** $p = .01$

Parental Approval: The majority of participants believed that leaving with the character in the vignette would elicit a negative evaluation from their *parent(s)*, although slightly more males predicted their parents would not be bothered by their behaviour; all the female participants said that their parents would think badly of them.

All of the female participants in the ID group, and the majority of the ND and PD groups stated that what their parents thought mattered a lot to them. The male participants in the ID group also said that their parents' views would matter a lot to them. In contrast, the males in the ND and PD groups were less concerned with their parents' views (table 9.10).

Potential Partner: Participants from the ND group were more likely than either of the two disability groups to predict a negative evaluation from the character of the opposite sex (*potential partner*) in the vignette, if they left with him/her. However it is clear that this difference was due to the responses from females in the ND group, the majority of whom

Table 9.10: Values Associated with Expected Evaluations for Leaving with the Character – Forced-Choice Questions

		No Disability		Intellectual Disability		Physically Disability	
Male Participants		<i>n</i> 16		<i>n</i> 17		<i>n</i> 15	
		A Lot	A Little	A Lot	A Little	A Lot	A Little
Unknown Peers	Positive	.13	.63	.12	.18	.13	.27
	Negative	0	.13	.18	.18	.07	.33
	Neutral	0	.13	0	.35	.07	.33
Close Friends	Positive	.31	.25	.18	.24	.20	.13
	Negative	.06	.06	.29	.18	.27	.27
	Neutral	.13	.19	.06	.06	.07	.07
Parents	Positive	0	0	0	0	0	0
	Negative	.19	.31	.59	.18	.27	.40
	Neutral	.25	.25	.12	.12	.20	.13
Potential Partner	Positive	.19	.50	.47	.12	.67	.27
	Negative	.06	0	.18	.06	0	0
	Neutral	.13	.13	.12	.06	.07	0
Female Participants		<i>n</i> 18		<i>n</i> 17		<i>n</i> 15	
Unknown Peers	Positive	0	0	.06	0	0	0
	Negative	.56	.44	.41	.35	.47	.47
	Neutral	0	0	.12	.06	.07	0
Close Friends	Positive	0	0	.06	.06	0	0
	Negative	.67	.11	.47	.24	.67	.20
	Neutral	.11	.11	.18	0	.07	.07
Parents	Positive	0	0	0	0	0	0
	Negative	.94	.06	1	0	.87	.13
	Neutral	0	0	0	0	0	0
Potential Partner	Positive	.17	.06	.24	.35	.47	.20
	Negative	.56	.22	0	.06	.07	.07
	Neutral	0	0	.24	.12	.13	.07

expected a negative evaluation. In contrast, males from the ND group more frequently expected the *potential partner* to respond positively. However such gender differences were much less pronounced for the ID and PD groups, with the majority of both males and females predicting a positive response.

With regard to the value associated with these evaluations, males in the ID and PD groups placed more value on the expected positive evaluations from the *potential partner* than did the ND group. However, females in the ID group were less likely to value the *potential partner's* positive evaluation of them than the female ND or PD participants. For females

in the ND group, the majority of whom expected a negative evaluation, most said that such an evaluation would matter a lot to them (table 9.10).

Open-Ended Responses: As shown in table 9.11. the male participants who predicted a positive evaluation from *unknown peers* or *close friends* for leaving with the character referred to expecting either general admiration or that they would be perceived as being confident with members of the opposite sex. Only one female from the ID group stated that *unknown peers* would think more of her, and said that she was engaging in normal behaviour.

The female participants who expected negative evaluations from *unknown peers* and *close friends* believed that if they left the party with the character they would be perceived as being irresponsible and foolish or as sexually promiscuous. These views were also shared by the smaller number of male participants who predicted a negative reaction. Participants from the ND group discussed this in relation to their safety, whereas responses from the ID and PD groups talked more about how their friends would be angry with them for doing the wrong thing. Several participants in the ID and PD group discussed the expectation that others would talk about them or like them less.

A large proportion of the expected negative evaluations from *parents* referred to parents being angry or disappointed. As with the alcohol section, whereas the ND group tended to anticipate their parents would be disappointed, participants in the ID and PD groups more frequently expected them to be angry. A number of responses also referred to the expectation that the parents would think the participant was irresponsible or foolish for leaving with a stranger.

With regard to predicted evaluations from the *potential partner* for agreeing to leave with him/her, all positive evaluations referred to being perceived as fun, confident and better liked by him/her. All the expected negative evaluations, most of which came from ND females, referred to the *potential partner* having a lower opinion of the participant and thinking of them as sexually promiscuous.

Table 9.11: Expected Evaluations for Leaving with the Character – Open-Ended Questions¹

			ND	ID	PD	Illustrative Quote
Unknown Peer	Positive Evaluation	‘Admiration’	Male 6	5	3	“Good one!” ND, Male, 18
		‘Confident’	Male 5	--	2	He's alright, he can get in with the lassies, he's confident” ND, Male, 17
	Negative Evaluation	‘Irresponsible’	Male 1	2	3	“Stupid, ‘cos leaving with a guy don't know, don't know what he can do”, ID, Female, 19
		‘Sexually promiscuous’	Male 1	2	--	
		‘Others would talk/laugh’	Female 3	5	5	“That I'm a complete slut. I'm disgusting”, ID, Female, 19
			Male --	3	--	“They wouldn't be very nice to me, they wouldn't like me”, ID, Male, 19
Close Friends	Positive Evaluation	Non-Evaluation	Male 1	1	--	“Probably be happy for me” ND, Male, 18
		Female --	--	1	--	
		‘Admiration’	Male 4	4	3	“Good on you, ‘cos he's a boy every girl fancies”, ID, Female, 18
	Negative Evaluation	‘Confident’	Male 3	2	2	“Think more of you, you can talk to the lassies”, ND, Male, 17
		Non-Evaluation	Male --	2	2	“They'd say you shouldn't do that”, ID, Male, 18
		Female --	--	--	--	
		‘Irresponsible’	Male 1	3	4	“Irresponsible, they might think its quite dangerous; they'd be worried”, ND, Female, 17
		Female 9	6	3		
		‘Others would talk/laugh’	Male --	3	1	“Slag me badly. They'd say she's not nice looking, gossip about me” ID, Male, 17
		Female --	6	6		
		‘Sexually promiscuous’	Male 1	--	1	“Think I was a bit slutty”, ND, Female, 17
		Female 5	--	2		
Parents	Negative Evaluation	Non-Evaluation	Male 5	8	5	“Be a bit worried that something happened to me” ID, Female, 19
		Female 2	2	3		
		‘Anger’	Male --	5	3	“Very disappointed. What we taught you went over your head”, ND, Female, 20
		Female --	12	7		
		‘Disappointment’	Male 3	--	--	“You naughty girl, getting on at me, shouting at me”, ID, Female, 17
		Female 12	1	--		
		‘Irresponsible’	Male --	--	2	“They'd be worried ‘cos I don't know him; probably think I'm careless, for safety or how they would feel if I went missing or turned up the next day”, ND, Female, 18
		Female 4	1	3		
Potential Partner	Positive Evaluation	Non-Evaluation	Male 1	4	--	“She would be happy” PD, Male, 16
		Female 1	--	--		
		‘Fun’	Male 5	2	4	“That I am a nice guy, fun to be with”, ND, Male, 17
		Female 3	5	2		
		‘Confident’	Male 4	3	4	“I am really good and confident”, PD, Female, 16
		‘They would like you more’	Male --	4	5	“She'd like you more” PD, Male, 16
		Female --	4	6		
	Negative Evaluation	‘Sexually promiscuous’	Male 1	1	--	“Respect me less, don't care about self. I guess they'd think you would sleep around”, ND, Female, 17
		Female 14	1	2		

¹Counts do not add up to group totals as neutral responses are not included in the table (see section 8.5.3).

9.3.2.2 Expected Evaluations for Refusing to Leave with the Character

Forced-choice responses and value placed on evaluations - Unknown Peers: Expected evaluations from *unknown peers* for not leaving with the character in the hypothetical situation were fairly equally distributed into positive and negative categories and the pattern was similar across the three groups. The one exception was that ND female participants more frequently predicted a positive evaluation than any other group (table 9.12).

Table 9.12: Expected Evaluations for *Refusing to Leave with the Character* – Forced-Choice Questions

		No Disability	Intellectual Disability	Physically Disability	
		<i>n</i> 34	<i>n</i> 34	<i>n</i> 30	
Unknown Peers	Positive	14	12	13	$\chi^2 = 2.31$; ns
	male: female	2 : 12	6 : 6	5 : 8	
	Negative	16	15	13	
	male: female	10 : 6	8 : 7	8 : 5	
	Neutral	4	7	4	
	male: female	4 : 0	3 : 4	2 : 2	
Close Friends	Positive	13	21	14	$\chi^2 = 9.96^*$
	male: female	4 : 9	10 : 11	4 : 10	
	Negative	1	5	4	
	male: female	1 : 0	3 : 2	3 : 1	
	Neutral	20	8	12	
	male: female	11 : 9	4 : 4	8 : 4	
Parents [†]	Positive	25	30	26	$\chi^2 = 3.99$; ns
	male: female	7 : 18	14 : 16	11 : 13	
	Negative	0	0	0	
	Neutral	9	3	4	
	male: female	9 : 0	2 : 1	4 : 0	
Potential Partner	Positive	12	2	3	$\chi^2 = 19.8^{**}$
	male: female	3 : 9	2 : 2	2 : 1	
	Negative	17	22	26	
	male: female	8 : 9	10 : 10	12 : 14	
	Neutral	5	10	1	
	male: female	5 : 0	5 : 5	1 : 0	

* $p = .01$; ** $p = .01$

[†]One participant from the ID group predicted a negative response from his parents

Male participants in the ND and PD groups associated little value with what their *unknown peers* thought of them, although one-third of males in the ID group said such views mattered a lot. With regard to females, more participants in the ID and PD groups stated it would *matter a lot* to them what their *unknown peers* thought than in the ND group (one-half versus one-quarter of participants). For males and females, value associated with

evaluations did not differ by the predicted direction of response (i.e. positive or negative; (table 9.13).

Table 9.13: Values Associated with Expected Evaluations for *Refusing* to Leave with the Character – Forced-Choice Questions

		No Disability		Intellectual Disability		Physically Disability	
Male Participants		<i>n</i> 16		<i>n</i> 17		<i>n</i> 15	
		A Lot	A Little	A Lot	A Little	A Lot	A Little
Unknown Peers	Positive	0	.13	.12	.24	.07	.27
	Negative	0	.63	.18	.29	0	.53
	Neutral	0	.25	.06	.12	0	.13
Close Friends	Positive	.19	.06	.29	.29	.20	.07
	Negative	.06	0	.12	.06	.13	.07
	Neutral	.50	.19	.12	.12	.33	.20
Parents	Positive	0	.44	.47	.35	.40	.33
	Negative	0	0	.06	0	0	0
	Neutral	0	.56	.06	.06	.13	.13
Potential Partner	Positive	.19	0	.06	.06	.13	0
	Negative	.44	.06	.29	.29	.33	.47
	Neutral	.19	.13	.12	.18	.07	0
Female Participants		<i>n</i> 18		<i>n</i> 17		<i>n</i> 15	
Unknown Peers	Positive	.17	.50	.18	.18	.27	.27
	Negative	.11	.22	.24	.18	.20	.13
	Neutral	0	0	.12	.12	.07	.07
Close Friends	Positive	.39	.11	.29	.35	.60	.07
	Negative	0	0	.06	.06	.07	0
	Neutral	.44	.06	.12	.12	.2	.07
Parents	Positive	.89	.11	.94	0	.93	.07
	Negative	0	0	0	0	0	0
	Neutral	0	0	0	.06	0	0
Potential Partner	Positive	.33	.17	0	0	.07	0
	Negative	.33	.17	.35	.35	.33	.60
	Neutral	0	0	.18	.12	0	0

Close Friends: With regards to *close friends*, as shown in table 9.12. participants in the ID group predicted more positive evaluations than the other two groups for leaving with the character, whereas more participants in the ND group expected their friends would not be bothered by their decision. Gender and group differences in value associated with *close friends*' evaluations were minimal (table 9.13).

Parental Approval: With the exception of ND males, the majority of participants across groups expected their *parents* to evaluate them positively if they did not leave with the character in the story. Over half of the ND males believed their parents would not be bothered. One male participant from the ID group did say his parents would think less of him, explaining that they would be curious why he turned her down.

There was a clear difference in the value male participants placed on expected evaluations from *parents*; no male in the ND group said it mattered to them what their *parents'* thought, where as approximately half of the males with ID or PD said it mattered a lot. Most of the female participants in all groups placed a lot of importance on their parent's opinions (table 9.13).

Potential Partner: As shown in table 9.12. the majority of participants predicted that the *potential partner* would evaluate them negatively if they refused to leave with him/her, with the exception of females in the ND group who were more likely to state that the potential partner would evaluate them positively. The ND group attached greater importance to these predicted evaluations. Most of the ND males and two-thirds of the females stated what the character thought of them would matter a lot to them, compared to approximately half the male and female participants in the ID and PD groups. Again, values associated with response did not vary with the direction of the predicted evaluation (table 9.13).

Open-Ended Responses: As shown in table 9.13., participants who expected a positive evaluation from *unknown peers* and *close friends* believed that others would see them as responsible and sensible for not leaving with the character. Several participants in the ND group referred to issues such as overcoming peer pressure, standing up for oneself and actively going against the crowd, which in turn would elicit respect and admiration from others.

Participants who anticipated that not leaving with the character would elicit negative evaluations from *unknown peers* and *close friends*, discussed how others would view them as 'strange', 'stupid' or 'stuck up' and would laugh or talk about them behind their back. A number of males, mostly from the ND group, also believed that others would think they were scared or unsure around members of the opposite sex.

Table 9.14: Expected Evaluations for Refusing to Leave with the Character – Open-Ended Questions¹

			ND	ID	PD	Illustrative Quote	
Unknown Peer	Positive Evaluation	Non-Evaluation	Male	--	3	1	It's your choice, good" ND, Female, 20
			Female	2	1	1	
		'Responsible'	Male	2	3	5	"Done the right thing, not go with someone met on one night" ID, Female, 16
			Female	9	5	7	
	Negative Evaluation	'Non - conforming'	Male	2	6	5	"That you aren't up for doing what the rest are doing, that you're a spoilsport" ND, Male, 20
			Female	2	--	--	
		'Boring'	Male	1	--	1	"Probably think I was being boring" PD, Female, 16
			Female	5	5	3	
		'You're scared'	Male	6	3	2	"That I am quite shy, weary about what to do, who to spend time with, where to go", ND, Female, 18
Close Friends	Positive Evaluation	Non-Evaluation	Male	--	4	1	"Happy that I'm safe" ID, Female, 19
			Female	--	4	1	
		'Responsible'	Male	4	6	4	"Probably same as parents, sensible" ND, Female, 19
			Female	9	6	7	
	Negative Evaluation	'Others would talk/laugh'	Male	--	3	2	"Probably laugh at you, probably you've missed your opportunity", ID, Male, 18
			Female	--	1	1	
		'You're scared'	Male	1	--	1	"They might think that I am shy, that I don't want to go" ID, Female, 17
Parents	Positive Evaluation	Non-Evaluation	Male	4	9	6	"Prefer it" PD, Female, 17
			Female	4	3	5	
		'Proud'	Male	3	5	5	"Quite proud, they'd be comfortable knowing I'm responsible and safe", ND, Female, 17
			Female	15	13	8	
	Negative Evaluation	'Not sexually promiscuous'	Male	3	--	--	"Show you more respect, think most girls would like you more, know that you wouldn't go with anyone else, showing respect for the girl", ND, Male, 20
			Female	9	--	--	
		'S/he would like you more'	Male	--	--	2	"Say nice guy" PD, Male, 19
			Female	--	2	1	
Potential Partner	Positive Evaluation	Non-Evaluation	Male	--	2	--	"Be upset" ID, Female, 19
			Female				
		'Boring'	Male	3	5	7	"Might think I'm not a nice person; boring" PD, Male, 17
			Female	4	2	6	
	Negative Evaluation	'You're scared'	Male	4	3	2	"Probably think you were scared too" ID, Male, 17
			Female				
		'Angry'	Male	--	2	3	"Leading him on about how much you liked him, he'd be quite annoyed", ND, Female, 18
			Female	6	8	6	

¹Counts do not add up to group totals as neutral responses are not included in the table (see section 8.5.3).

The majority of female participants across groups expected others to think they were boring. Participants who believed their parents would think better of them for not leaving

with the character generally discussed how their parents would be proud of them for making the right and sensible decision.

With regard to expecting a positive evaluation from the *potential partner*, participants in the ND group believed that they would respect them more as they did not appear sexually promiscuous. For the ID and PD groups, all responses referred to the partner liking the participant more, but did not specify why. The types of expected negative evaluations from the *potential partner* upon turning him/her down referred to them thinking the participant was boring, scared or the expectation that the partner would be angry with them. With regard to 'anger', ND and PD female participants expected the 'partner' to think they were leading him on, but no participant from the ID group explicitly mentioned this.

9.3.2.3 Social Goals Associated with Potentially Risky Sexual Behaviour

As shown by table 9.15., with the exception of ND males, the majority of participants across groups said they would not leave with the character. With regards to gender differences, male participants more frequently stated they would engage in the potentially risky sexual behaviour than female. The reasons cited by participants for leaving with the character did not relate to an evaluation, but generally referred to liking the guy/girl and/or wanting to get to know him/her better. Only two participants from both the ID and the PD groups stated that they would leave with the character in order to either avoid a negative evaluation (being seen as immature), or promote a positive evaluation (being seen as 'one of the gang').

Of the participants who said they would not leave the party with the guy/girl, the majority explained their choice with reference to safety, for example saying that they did not know the person and that leaving with a stranger could put himself or herself in potential danger. Two males in the ID and PD groups said that they would not leave with the character because their *parents* would disapprove of this, even when they were asked to imagine there would be no possible repercussions for their behaviour. Five female participants in the ND group referred to self-evaluations as the reason for not leaving with the guy, for example to avoid feeling cheap or worthless. A few participants also stated that they would not leave with the guy at the party because others would talk about them.

Table 9.15: Social Goals for Leaving or Refusing To Leave With the Character

		ND	ID ¹	PD	
Would leave with character*		15	6	5	
	Male	13	6	5	
	Female	2	--	--	
Social Goal					
Non-Evaluation	Male	13	4	3	“Probably go back to hers, ‘cos she’s good looking”
	Female	2	--	1	ND, Male, 18
Promote positive evaluation	Male	--	1	1	“Not sure, can’t answer that, yes I would go to be part of the gang”, PD, 16, Male
Avoid negative evaluation	Male	--	1	1	“Yeah, so other people at the party don’t think I’m a wimp, immature like”, PD, Male 19
Refuse to leave with character*		19	27 ²	25	
	Male	2	10	10	
	Female	17	17	15	
Social Goal					
Safety	Male	2	6	8	“Stay at the party, to be safe” PD, 17 Female
	Female	11	13	9	
Avoid negative evaluation...					
...from parents	Male	--	2	2	“So parents wouldn’t think I was silly” ID, Male, 19
...from peers	Female	1	2	1	“I would be a bit concerned because of everyone there, what they said about me”, PD, Male, 16
...self	Female	5	--	--	“I would feel cheap in myself” ND, Female, 18 “Wouldn’t, not the first night, I’ve more respect for myself than that” ND, Female, 25

¹One Male participant from the ID group gave no response; ²Two Male and two female participants could not say why they would not leave with the character. * $\chi^2 = 12.4$; $p = .002$

9.4 Conclusion

The main findings from Phase II are summarised here, firstly in relation to the risky alcohol scenarios and then for the risky sexual scenarios.

9.4.1 Alcohol Scenes

The most striking finding was that young people with intellectual disabilities, and to a lesser extent those with physical disabilities, held more negative beliefs about risky drinking than their non-disabled peers. These findings are consistent with reports of higher levels of abstinence and lower prevalence of drinking for people with intellectual disabilities (chapter 2; Beange et al., 1995; Edgerton, 1986; Lawrenson et al., 1995; McGillicuddy and Blane, 1999; Pack et al., 1998; Rimmer et al., 1995; Robertson et al., 2000; Wells et al., 1997; Emerson and Turnbull, 2005). These findings also chime with participants' responses in Phase I, where young people with disabilities discussed fewer positive outcomes associated with alcohol consumption than the ND group.

All participants were aware that to *refuse* a drink could result in social exclusion, for instance causing others to perceive them as antisocial, boring, immature and 'not part of the group'. Moreover, half of the non-disabled group and a third of those with physical disabilities said that they would take a drink to promote a positive image of themselves or to avoid others viewing them negatively. Hence, the non-disabled participants' more permissive attitudes about getting drunk seemed to reflect a view of binge drinking as a socially normative and appropriate behaviour in social contexts such as at parties.

Some of the young people with intellectual disabilities held conflicting views, believing that to accept the drink would cause others to negatively evaluate them, yet also believing that to refuse the drink could cause social exclusion. In addition, they tended to attach more significance to these negative evaluations than the other two groups; '*if I accept the drink I will look like an alcoholic, yet if I refuse it, I will look boring*', perhaps suggesting a very rather ambivalent attitude towards alcohol. The finding that young people associated risky drinking with both positive and negative social consequences may not be surprising in light of the copious, but often conflicting, messages received about alcohol. For example, the media portrays young people's drinking as fun, sexy, desirable and harmless,

whereas health campaigns and formal education programmes highlight alcohol's detrimental effects on health.

However, despite being aware of the social consequences of choosing to refrain from drinking, nearly all the ID group stated they would *not* accept the drink they were offered in the vignette, as did two thirds of the PD group. For these participants, more important than being perceived negatively by others was to the wish to remain safe (*'I wouldn't want to get to drunk'; 'it wouldn't be safe to accept another drink'*). No participant in the ID group said they would drink to promote a positive image of themselves, and this might lead us to imagine that they would be less likely to drink to excess than the other two groups. This refutes the suggestion often proffered in the literature, that the social benefits of engaging in risky behaviour, such as peer group acceptance, are important determinants of behaviour among adolescents with intellectual disabilities (Hymowitz et al. 1997; Kalyva, 2007).

Nevertheless, Gibbons, et al. (2009) discuss how it is perhaps harder for people without prior experience of behaviours to predict accurately how they would respond in a given situation. Owing to the compromised social networks of the participants with ID and PD, these individuals may have had fewer opportunities to drink in social situations. Therefore, many of the ND participants often seemed to draw on their own past experiences when explaining their social goals (*'that is just something I always do'*) and so knew how they would react and feel in these situations, something which was not available to participants in the two disability groups:

“I would keep drinking, I know that's what I do, I don't stop until I fall over, for confidence, I don't know, the people, it makes you feel more relaxed and easier to talk to (*and how would that make you feel?*) Probably disappointed because I know I should have stopped, but I won't let it show”.

ND, male, 16

As discussed in section 8.4., incongruities between the situation or characters in the vignette and the participant's actual experiences will impact upon the participant's ability to imagine themselves in the hypothetical situation. This reflects a potential limitation of using this method with young people with disabilities who may have lacked previous experience in these situations. On the other hand, having poorer awareness and understanding of these social situations may leave individuals unprepared or vulnerable if

such situations do arise. Therefore, the use of such hypothetical situations might provide insight into the vulnerabilities of young people with disabilities. This latter point is discussed further in the main discussion (section 10.3.7).

With regard to predicted reactions from close friends, we may expect that these attitudes and behaviours would mirror more closely the participants' own reactions, as close friends often share similar outlooks (Berndt and Murphy, 2002; Newcomb and Bagwell, 1995). In line with this prediction, the ID and PD groups more frequently expected that their friends would react negatively to accepting the drink than the ND group. In turn, this fitted with the findings that few of the ID and PD participants drank alcohol when they socialised with others, and that in the situation described in the vignette they would also not choose to drink. The ND adolescents were more likely to say that their friends would not be bothered if they accepted a drink or not, suggesting a more relaxed and accepting attitude to alcohol use. Although there were no group differences in the value associated with friends' reactions, ND and PD participants valued their friends' opinions *more* than the unknown peers. However, the differences between the value attached to close friends' and unknown peers' views was less marked for the ID group.

It has been previously suggested that people with intellectual disabilities may be more influenced by their parents' attitudes, as they often remain more dependent upon them (Whitaker and Hughes, 2003; see also phase I data). The current findings provide some support for this view. The majority of participants expected parents to have negative attitudes toward drinking, although non-disabled adolescents more frequently expected their parents not to be bothered. Moreover, parental opinions mattered more to the young people with disabilities than their non-disabled peers, suggesting that young people with disabilities may be more influenced by their parents' views and beliefs. There was also a subtle and important difference in the types of reactions participants predicted from their parents for accepting the drink. While the ND group said their parents would be *disappointed*, young people with disabilities stated their parents would be *angry* with them. This would imply that parents have greater influence in the lives of young people with disabilities, as anger would suggest that they have disobeyed a command. Whereas, disappointment suggests that parents have given their offspring the freedom to make their own choices as adults, although they still have expectations that they will behave reasonably. It should be emphasised that that the majority of participants in the ID group

were over the age of eighteen and therefore legally entitled to consume alcohol. Thus parents continue to play a central role in the lives of these young people with ID, and may continue to shape their views at a stage where other young people are commonly gaining more independence. Undoubtedly, the transition to independence can be more complex for young people with disabilities, for instance with very real issues of dependency and vulnerability, so care has to be taken to avoid blaming families for these continuing close ties. The picture was indeed very different for the ND participants, valued close friends' opinions more than those of their parents. This reflects the typical pattern during adolescence, when familial ties are loosened and peer affiliations become more salient (Brown, 1990).

Care has to be taken when interpreting these findings. One simple interpretation of the non disabled participants' more permissive outlook towards drinking might be that the disabled groups were more sensitive to the health agenda underlying the questions. Indeed, they did demonstrate fairly good knowledge about the health impact of alcohol (Phase I data). However, the differences in anticipated attitudes from close friends and parents are consistent with another explanation, that the social construction of adolescence is different for young people with disabilities. Risk taking is often associated with the transition towards adulthood, yet for young people with disabilities opportunities to engage in situations where alcohol is present and away from parental supervision are limited. Being more closely supervised and allowed less independence, as well as having impoverished social networks may also account for the differences in attitudes expressed toward alcohol. Thus, the fact that people with disabilities have different experiences with alcohol from their non-disabled peers may also be symptomatic of their social exclusion (Simpson, 1998). Research exploring alcohol-related behaviours and attitudes in adults with intellectual disabilities invariably comes from a risk and management perspective where alcohol use is construed as a 'problem'. However, this ignores the fact that for many young people, alcohol is meaningful and fulfils important social functions, such as facilitating friendships, maturity status and exploring personal identities (Jessor, 1984; Maggs, 1997; Spruijt-Metz, 1999). Experimenting with alcohol is seen as one of the developmental tasks of adolescence (Schulenberg et al., 1996).

9.4.2 Sexual Behaviour Scenes

The picture regarding the sexual scenarios is more complex, reflecting both between group differences and within group differences in terms of gender, both of which are discussed below. For female participants, there were many similarities in attitudes across the three groups. On the whole, females expected their peers and friends to view sexually promiscuous behaviour negatively and hold positive attitudes toward more conservative behaviour. More reactionary attitudes towards sexual expression by women have been reported in previous studies (Hooke, Capewell and Whyte, 2000; Moore and Rosenthal, 1992; Oliver and Hyde, 1993; see below). Even when adolescent females do express sexual desire, they may fear the negative effect this will have on their reputation (Tolman, 1994) and more frequently report feelings of anxiety or guilt about sex (Oliver and Hyde, 1993).

However, several females expected to receive a negative evaluation from others at the party situation depicted in the vignette if they did *not* leave with the male character, believing that to refuse would make them appear 'boring' or 'stuck up'. This suggests two competing belief systems may be operating. On the one hand these women were aware that to behave in a sexually promiscuous fashion is not endorsed by friends and parents, but at the same time to engage in such behaviour can be the norm for others. Young people are bombarded with messages and images from the media and the adult world about their sexuality, often presenting casual sex as the norm. It might be argued that such mixed messages leave young women feeling confused or ashamed about their sexuality and less well prepared to make decisions about sexual matters (Tolman, 1994).

More young men than women in the non-disabled group expected to be viewed favourably by peers and friends for engaging in the risky behaviour (being admired or seen as confident around females) and unfavourably for refusing (unconfident around females, not fitting in with the group). Yet it was noteworthy that these gender differences were much less obvious for the two disability groups. Overall, responses given by males in the ID and PD groups were more equally distributed between positive and negative responses. However, males in the ID group expected their close friends to evaluate them more positively for abstaining from the risky behaviour than the other two groups did.

The findings from the ND group are consistent with past research demonstrating that one of the main reasons given by young people for having sex was to impress their peers (Hooke, Capewell and Whyte, 2000). With regard to the apparent gender differences, these findings also fit with previous research suggesting that males expect their friends to be more positive about their sexual prowess than females (Moore and Rosenthal, 1992). For instance, Hooke, Capewell and Whyte (2000) reported that in a sample of Scottish teenagers aged 14 – 15 years of age, over four times as many males than females thought casual sex was acceptable, whereas the majority of females believed that some commitment had to be present for sex to be acceptable. A meta-analysis of 177 studies found that males demonstrated more permissive attitudes toward casual sex than females (Oliver and Hyde, 1993). Men also reported having more sexual partners and being younger when they first had sexual intercourse. Taken together, this suggests that ND males have more liberal attitudes toward sexual expression, and also expect others to share these attitudes.

Although the finding that young people with disabilities viewed risky sexual behaviour more negatively than their ND peers might be seen as an encouraging from a health promotion perspective, it also highlights differences in the background experience of young people with and without disabilities. For example, it would appear that young men with disabilities are being exposed to more negative attitudes toward sexuality than their non-disabled peers. These negative attitudes are likely to stem from society in general, from having limited opportunities to express their sexual desires, and also from the negative attitudes of parents and significant others. For instance, the majority of young people expected their parents to have negative attitudes towards them engaging in potentially promiscuous behaviour, with the exception of non-disabled males who expected their parents to have more liberal attitudes. Thus, the men with disabilities did not benefit from the *sexual double standard* - society's permissive attitudes toward male promiscuity and intolerance for female promiscuity. Darling and Hicks (1982) found that parental messages were discouraging of sex to male and female adolescents, but that the negative consequences of sexual activity were far more strongly stressed for daughters than for sons. In accord with this, the current study found that females more frequently discussed the importance of being seen as responsible/sensible and issues of safety than males.

Some of the young men with disabilities did allude to their sexual desires, in so far as approximately one-third of them said that they would choose to leave with the female character if they were in this situation. Unfortunately though, this was accompanied by a strong sense of others' negative attitudes towards their sexual expression. If this reflects the dilemma that these young people face in their everyday lives, then one could imagine that it could lead to feelings of discomfort, shame and guilt, and a lowered sexual self-concept (McCabe, 1999).

Once again, with regard to the anticipated reactions from the potential partner in the vignette, there were clear gender differences in the ND group. Males in the ND group believed that leaving with the female character would be viewed positively, whereas not leaving with her would be viewed negatively. Whereas, for ND females, the majority expected a negative evaluation for leaving with the male character (being perceived as sexually promiscuous) and more frequently expected a positive reaction for not leaving with him (eliciting more respect from the male).

These gender differences, with regard to the potential partner's views, were absent in the two disability groups. With regard to the females with disabilities, they anticipated a positive response from the character for behaving in a sexually permissive fashion. This could mean that the ND females had a clear conception of society's negative outlook on what is regarded as 'promiscuous' behaviour, than those with disabilities. It could also reflect a lack of experience of being in such social situations or making these kinds of decisions. However, it would have been informative to know whether the women were making a positive choice, as women with intellectual disabilities have been reported to be more likely than men to have sex because they are being coerced or wish to maintain a relationship (McCarthy, 1999).

Chapter 10: Discussion & Recommendations

This chapter summarises the key findings of the thesis and considers the implications of these findings for policy and practice. In addition, it provides a critical reflection with regard to the strengths and limitations of the study and provides new avenues for research.

10.1 Main Findings

This research has highlighted the importance of people's unique learning and socialisation experiences in shaping not only their health knowledge, but also their attitudes and beliefs. A substantial part of the research process was concerned with the development and piloting of appropriate methods with which to address these aims. Through structured and semi-structured questionnaires and vignette-based methodology, data from over 100 young people has been analysed and interpreted.

The main findings of the thesis will be discussed with reference to the aims and objectives of the study outlined in chapters 5 and 8. In summary, this study has explored the following in young people with and without disabilities:

- the similarities and differences in their health knowledge, both in terms of understandings and misunderstandings.
- the nature of their social networks and reported access to sources of health information, thereby gaining an understanding of the relative impact of i) having a cognitive impairment and ii) social exclusion upon health knowledge.
- their beliefs about others' attitudes towards engaging in, or refraining from, potentially risky alcohol and sexually-related behaviours, as well as the value they attached to others' views.
- their salient social goals (or motivations) for engaging in or refraining from these risky behaviours.

The notion that a lack of health understanding and different attitudes and beliefs merely reflect the personal inadequacies or functional limitations of young people with intellectual

disabilities has been challenged. Instead, it is suggested that greater attention should be paid to the social, environmental and attitudinal barriers that influence the health understandings and beliefs of young people with intellectual disabilities. Although such a perspective has been adopted in the broader disability literature, through the Social Model of Disability (Oliver, 1983), it has been given limited consideration in relation to people with intellectual disabilities (see Oliver 1990; 1996). In exploring young participants' social networks and access to sources of health information, this research has also helped to identify barriers to health understanding in general, and sexual understanding in particular. Consequently, it is hoped that the findings contribute to an understanding of the impact of social exclusion for these young people and helps to identify effective means of getting relevant health information across to them.

10.2.1 Health Knowledge and Understanding

As expected, young people without disabilities demonstrated more sophisticated understanding about health across the four topics than young people with intellectual disabilities. It was noted that although the physical disability group shared similarities in understanding with both of the groups, they were more similar to the ND group with regard to 'public' health topics (healthy eating and alcohol) and more similar to the ID group on 'private' topics (pregnancy/contraception and HIV/AIDS). This supports the idea that a lack of sexual health knowledge did not arise from cognitive difficulties alone. Instead, compromised social networks and lack of autonomy meant individuals with disabilities had limited access to sexual information. Additionally, this also hindered participants' opportunities for experience and experimentation.

10.2.2 Social Networks

The findings from this study are consistent with UK government policy guiding services for people with learning disabilities, which emphasise the benefit of social inclusion (*The Same as You?* Scottish Executive, 2000; *Valuing People* - Department of Health, 2001). However, despite 'choice and control' being a consistent theme in these policy documents, the participants in this study had limited autonomy and usually remained under the supervision of families or carers, perhaps to a degree that their non-disabled peers would not accept (Scior, 2003). Beyond family relationships, the research found that participants

with intellectual and physical disabilities on the whole had impoverished social networks when compared to their non-disabled peers. This has been a consistent finding in the literature (see chapter 3). Not only did participants report fewer close friendships within or outside the school or college than their non-disabled peers, they also reported engaging in fewer leisure time activities with friends and spending more time in solitary activities within the home.

It may be expected that for the young person living at home, the family will be more central in their support network than perhaps it will be in later years. However, as adolescence is typically a time when family influences become more peripheral and peer influence more central, we would expect friendships to form a larger proportion of young people's networks (Levitt et al., 1993). This was only found with the non-disabled group. Although families will be able to meet some of the young person's needs, friends may be able to provide unique support functions the family cannot (McVilly et al., 2006a). For instance, friends may play a particularly important role in helping people deal with unpredictable life crises (Llewellyn and McConnell, 2002) as they may have less set expectations about the course their friends' lives are likely to take.

People with intellectual disabilities tend to have more dense social networks, with a higher proportion of members within the social network being interconnected or known to one another (Forrester-Jones et al., 2006). In the current study, many of the young people with disabilities had the same friends and few had contacts external to the school/college. In contrast, participants without disabilities reported having more diverse networks, which included individuals from other schools and colleges, clubs and societies. As discussed in chapter 3, having a network that connects an individual with people from different backgrounds and groups (bridging social capital) can help to meet a range of practical and emotional needs. It is quite common that young people's friendships are initially based on proximity and similarity. In other words, young people might be more likely to make friends with other people in their classes who are of a similar age and gender. Yet for friendships to become deeper and sustainable they may need to extend beyond the school setting (Matheson et al., 2007).

The lack of access to social activities meant that these young people had limited opportunities for informal and spontaneous interactions with peers. Such peer interactions and relationships have been shown to be of great significance for developing social skills,

rehearsing and experimenting with behaviour and social roles, and for the sharing of knowledge, attitudes and values (Cole et al., 1993; Hartup, 1993). McCarthy and Thompson (1992) argue that knowledge about sex is acquired gradually through our everyday experiences and interactions with others. This may take the form of 'euphemisms, jokes and hints', as well as more formal sources (1992, p4). Thus, the young people with disabilities in this study, as articulated by Davies (2000), were being "excluded from most of the dominant socialisation processes that help teach and prepare people for love, sex and intimacy" (p. 188). Moreover, a lack of friends not only limited participants' access to informal sources of information, but also who they could form relationships with, including potential sexual or intimate partners.

10.2.3 Sources of Health Information

Overall, the similarity in number and types of sources of information accessed by the two disability groups suggests that it was not just ability to understand information that proved problematic for the young people. They experienced additional barriers to accessing this information. Although data was not collected on the factors that influenced whether young people had accessed a particular source or not, a few themes emerged from the research which may elucidate this. To be able to explore this further, in the following sections, findings from across the different stages of research will be drawn together. It is hoped that this will help to provide greater insight into the challenges that young people with disabilities face in accessing health information, and especially about sexual health.

There are two noteworthy findings in relation to where young people access their health information. Firstly, those participants with ID and PD demonstrated less diversity in the sources that they had accessed in relation to health when compared to their non-disabled peers. Young people without disabilities relied on a variety of sources for health information and although this included formal sex education, such as schools and health professionals, principal sources included friends, books, magazines, and the mass media. Having an array of sources from which to access information is important, as this helps adolescents to sort through the sometimes highly confusing and contradictory messages that they receive in relation to health. For the young person with a disability, not having the same opportunities or experiences as their non-disabled peers makes it difficult for them to

contradict any (false) information presented to them; in other words, to unravel fact from fiction.

Secondly, there were clear differences in *who* young people spoke to about health, most significantly with friends and family having been accessed less frequently by people with disabilities, and this is the matter that will now be turned to.

10.2.4 Communication about Health Matters: Friends

Participants with disabilities reported having spoken to their friends about health, notably sexual health, less than their non-disabled peers. This suggests that the opportunities to learn about health available to non-disabled adolescents were lacking for these young people. At the most fundamental level, actually *having* friends to share information and confide in is crucial. Unfortunately, this study has not been able to affirm definite associations between the size of participants' social networks and whether or not they had spoken to their peers about health matters. However, there are two possible explanations for the lack of association between social networks and their reported sources of health information. These explanations relate to characteristics of their friendships and their attitudes toward health behaviours.

While it might seem intuitive to say that the more friends an individual has and spends time with, the more likely it is that they will discuss issues around health. Yet this is probably an over simplification. For instance, in relation to sexual health, owing to its personal and sensitive nature, individuals are likely to be selective with whom sexual matters are discussed. Characteristics of the friendship, such as intimacy and trust, are probably more significant in determining whether discussions take place than the number of friendships a person has. Abraham et al. (1991) reported that adolescents' discussions about AIDS were most likely to occur in intimate, peer group relationships and with same-sex friends and partners who were expected to have similar attitudes toward AIDS. For the two disability groups the majority of the friendships participants discussed were formed through school/college, yet it was very rare that these would be continued outside of the school/college setting. Thus, for some individuals, opportunities for these friendships to develop in terms of intimacy, trust, support and reciprocity may have been limited. The idea that having a large social network does not guarantee an individual's socio-emotional support needs are met is illustrated though the work of McVilly and his colleagues in

chapter 3. McVilly et al., (2006a) demonstrated that associations between self-ratings of loneliness and social networks were complex; individuals with larger social networks did not necessarily report being the least lonely. On the contrary, feelings of loneliness were determined by the quality of relationships and their ability to meet the individual's needs.

An insight into why young people did not discuss health matters with their friends was also gained from Phase II of this research, which demonstrated that young people with disabilities held more negative views and expected others to express negative views towards their engaging in risky drinking and sexual behaviour. Fear of a negative evaluation or ridicule is likely to play a large role in the adolescent's willingness to initiate a topic with peers. In relation to this, having a lack of knowledge itself may be a barrier to discussions about health, especially sex. For instance, not wanting to appear inexperienced may prevent an adolescent asking questions of his or her peers, thus further contributing to the propagation of myths. Finally, personality variables, such as timidity and reservedness may be associated with accessing information about sexual matters (Wellings et al., 1995).

10.2.5 Communication about Health Matters: Family

Surprisingly, given that the participants with disabilities had fewer friends, they were less likely to report speaking to family members about sexual health matters. In fact, whereas over 80% of the ND group had discussed sexual matters with their family, this compared to 35% and 38% of the ID and PD groups, respectively. Possible reasons why people with disabilities are less likely to have discussed sexuality matters with their family were discussed in chapter 3. These include characteristics relating to both the parent, such as lack of confidence, reluctance to see their child as a sexual being, fears of vulnerability (Cheng and Udry, 2003), and also to the young person, such as embarrassment and fear of negative reactions (Morrison, 2006). Some of these past findings have been replicated in this study, with the young people who have intellectual and physical disabilities anticipating more negative reactions from their parents if they engaged in a risky alcohol or sexual behaviour than their non-disabled peers. As discussed by McCabe (1999), anticipating negative attitudes or feelings will have a direct impact upon whether a topic, such as sexuality, is discussed.

Participants had developed clear notions of how their peers and family would react if they did engage in risky behaviours, even though they probably had not discussed these kind of

situations with anyone before because they had few opportunities to engage in behaviours such as drinking or attending parties. However, the transmission of attitudes and values does not have to be direct and by saying nothing about sexuality to their child, a parent is in fact saying *something*. They may be conveying negative messages about sexuality to their child, either intentionally or inadvertently; in other words, that sexual expression is not appropriate (McCabe, 1999; McCabe, Cummins, Reid, 1994). Not discussing their thoughts and feelings with others may result in the individual having negative attitudes and unnecessary worries and tensions. This can lead to discomfort with their sexuality and feelings of shame and guilt, which in turn may lead to a lowered sexual self-concept (McCabe, 1999).

The risk of sexuality remaining a ‘private’ issue that can not be talked about openly is that it takes on negative connotations and is seen as being ‘dirty’ or ‘taboo’, associated with embarrassment and shame. For instance several male participants in the ID group stated that they would want to leave with the female character in the vignette, yet anticipated that their friends and parents would think unfavourably of them if they did. As these opinions mattered to these young people, engaging in such behaviour may leave them feeling ashamed. This in turn may leave them unprepared and vulnerable if such situations do arise. In addition, perceived negative attitudes may prevent young people accessing other sources of information. For example, young people with disabilities were less likely to report having accessed a health professional or clinic for information about sexuality than their non-disabled peers. Although this may reflect poor awareness of the services available to them (Fraser and Sim, 2007), perceiving others to have negative attitudes toward sexual behaviour may also prevent services being accessed, for example fearing that their parents might ‘catch’ them doing so.

10.2.6 The Media

If young people do not have safe spaces in which to discuss and normalise sexuality, such as friends and family, they are forced to turn to other less reliable sources for related information, such as the media. Over half of the participants in each group stated that they had received information about sexual health, including HIV, from the media, as did an even larger number of participants for information in relation to alcohol and healthy eating. The finding that the mass media plays an important part in influencing young people’s

sexual health knowledge and beliefs has been reported previously (Abraham et al., 1991). It has been suggested that teenage magazines have a major role in sexual health education, as they discuss topics openly and can tackle issues of pleasure and desire that perhaps cannot be addressed elsewhere (Wellings, 1996). Owing to poor literacy, using printed media was not a viable option for the ID group. Instead, the most commonly reported place where these participants obtained information about sexuality was the television. It has been argued that the information and situations portrayed on television are often far removed from an individual's own experiences that information becomes virtually useless (McCarthy, 1999). Therein lies the difficulty, by relying on one source for information but being unable to discuss their thoughts and feelings about this information, young people are unlikely to dispel myths and may tend to take what they see on television as fact (McCabe, 1999). People with intellectual disabilities may idealise love and relationships (Arias et al., 2009; Knox & Hickson, 2001), perhaps a consequence of having few positive role models and the lack of access to realistic information (Gordon et al., 2004; Howland and Rintala, 2001; Lesseliers & Van Hove, 2002).

Young people may receive contradictory messages about sexual behaviours. For instance, on one hand individuals are warned of the risks of being sexually promiscuous by parents, formal sex education, and media campaigns, yet on the other the hand, television and films frequently portray casual sex and sexual activity positively and as something to be desired (Batchelor and Kitzinger, 1999). This was reflected in the findings of phase II of this research. Females believed that engaging in a risky sexual behaviour could risk their reputation, for instance being regarded as 'easy' or 'cheap'. At the same time, to not engage in the behaviour was also risky, causing the female to be regarded as 'boring' or 'frigid'. Such contradictory and confusing messages can be worrying and anxiety provoking for young people, leaving them unprepared for such a situation should it arise. An example of this is that women may avoid carrying condoms due to fears about the risk to her reputation, as she could be perceived as someone who actively seeks sex (Hillier, Harrison and Warr, 1998).

10.2.7 Formal Sex Education

The majority of young people obtained health information from school and this was the predominant source of information for the two disability groups. Others have argued that

“formal sex education for people with learning disabilities is clearly more significant than for other adults” (McCarthy and Thomson, 1992, p4) owing to the lack of alternative sources. Nevertheless, sex education provided in schools has often been criticised for concentrating on biological aspects of sexuality at the expense of the more emotional and interpersonal elements like desire, pleasure and the rules and norms for engaging in intimate relationships (Thompson and Scott, 1991). This is despite the fact that young people themselves place greater importance on the latter (Allen, 2001). It is perhaps not surprising then that research has found young people view sex education in schools as supplementary to other sources, such as friends, the media and personal experience, as opposed to being their main source for sexual information (Buston and Wight, 2002). Unfortunately, talking to friends, or even family, was not a viable option for young people with disabilities in this study. For instance, young people with disabilities in this research were less well informed about the practical aspects of obtaining or using contraceptives than their non-disabled peers. It would seem that school can inform young people about *what* contraception is/does, however it is friends and other informal sources that young people use to fill in the specific details, such as *how* to actually do things (Allen, 2001; Buston and Wight, 2002).

Social constructionist accounts of sexuality, which describe sexuality as learnt from everyday experiences and interactions, may be relevant to the experience of young people with disabilities. Gagnon and Simon (1974) discuss this in terms of ‘sexual scripts’, or learned rules of sexual behaviour, which provide guidelines and context for appropriate sexual behaviour and sexual encounters. As ‘sexual scripts’ are learnt from our everyday social environment, including interactions with others, formal education, the media, and personal experience, it has been argued that individuals with disabilities may have “altered scripts” (Couwenhoven, 2007; McCarthy, 1999). This can negatively impact upon an individual’s self-concept as well as vulnerability. Of course, it should be stressed that it is not always appropriate for schools to address issues such as pleasure and desire, particularly as their primary objective is to avoid sexual experimentation and early initiation (Wellings, 1996).

10.2.8 Discourses of Vulnerability, Risk and Protection

Although many parents work hard to allow their son or daughter to experience full and fulfilling lives, this can be moderated by a desire to protect their child from harm (Cole and Cole, 1993), what Scior (2003) referred to as the ‘Guardianship Discourse’. The possibility that young people with disabilities have been exposed more to a protectionist discourse was revealed in their responses to the vignettes. Young people with disabilities, particularly in the ID group, tended to use a discourse of safety in both the alcohol and sexual scenarios, discussing the importance of avoiding harm to themselves and others. Many participants seemed to be reciting rules such as ‘you shouldn’t drink off a stranger’ which were then used to explain why they would choose not to engage in the behaviour. Conversely, the non-disabled group more frequently used discourses of ‘having fun’ and ‘socialising’.

In relation to sexuality, this discourse of safety appeared more gender specific, but for the non-disabled group only. In the sexuality scenes females in all groups frequently discussed the importance of being safe and appearing responsible. It appeared that female participants had been exposed to gendered discourses emphasising their vulnerability and the avoidance of sexual promiscuity. For instance, females frequently stated that it is wrong to ‘sleep with a guy on the first night’ and ‘you shouldn’t give in’ too easily. On the other hand, the fact that non-disabled females predicted that the potential partner would have more positive views of them for refusing to leave with him suggests that these participants felt empowered to say ‘no’, if that is what they chose. Females in the ID and PD groups did not give such responses, believing the potential partner would react negatively if they refused to leave with him (and a positive reaction if they agreed). The fact that these participants said that they would not leave with the character if they were in this situation highlights the importance of self-esteem and assertiveness, in ensuring that these individuals feel able to follow their choices through.

For ND males, behaviour was more about proving one’s sexual prowess. This suggests that these males have been exposed to a ‘predatory discourse’ of sexuality, which views them as initiators of sexual behaviours and, in turn, sexual behaviour as a way to establish a masculine identity (Wight and Henderson, 2004). This is reflected in the finding that the majority of ND males stated they would leave with the character in the vignette, suggesting

that such behaviour was normal and perhaps even expected of them. The fact that gender differences were less marked in the two disability groups suggests that different norms were being communicated to many of the males with disabilities; essentially that sexual behaviour was not appropriate (denying them a sexuality) or acceptable (that sexuality is wrong). However, as discussed in section 5.10.1, gender-of-interviewer effects should be borne in mind when interpreting this data.

Often in the drive to protect young people and shelter them from harm, adults may avoid addressing sensitive topics, yet this can lead to increased vulnerability if the young person lacks the knowledge, skills and understanding they need to lead confident, healthy and independent lives. Although the finding that young people had negative attitudes toward engaging in potentially health risking behaviours is encouraging from a health perspective, it also implies something quite significant about the lives of young people with disabilities. It seems they had little opportunity or encouragement to develop or explore these aspects of their personhood, in relation to their sexuality and social identities, which are central to the lives of those without disabilities.

10.3 Implications of this Research

10.3.1 Introduction

This research has demonstrated how young people with disabilities may be excluded from the opportunities to learn about and experience health-related behaviours, in particular sexual health and relationships, available to their non-disabled peers. This in turn can impact upon the development of health knowledge and attitudes. Therefore, if we are to empower young people to take more control over their own health and sexuality, this will necessitate more than the transmission of knowledge and skills. A multi-faceted approach is needed and this will entail working with the individuals themselves, their families and support networks, health services, schools and further education colleges, as well as attempting to combat social isolation. Findings from a recent review of Sex and Relationship Education Programmes in Scottish secondary schools reinforces this sentiment, reporting that effective interventions should cover biological, cognitive and social developmental factors in adolescents. Moreover, interventions should address social

and media influences on sexual behaviour and involve parents and peers in their delivery (Health Scotland, 2008).

In the following sections, implications of the findings from this study will be discussed in relation to the delivery and designing of health education curricula, as well as focusing on the ways of addressing the social barriers faced by young people with disabilities in learning about health.

10.3.2 Implications for the Delivery of Sexuality Education

10.3.2.1 Developing Innovative Methods

The current study shows that participants' varying levels of impairment, alongside differing experiences, motivations and interests, makes it difficult to produce a 'one size fits all approach' when it comes to health education. It is imperative that the starting point is always the young person; with information tailored to their specific needs, levels of knowledge, understanding and learning styles. This will ensure that the subject matter is appropriate, interesting and relevant. Through the use of innovative and carefully designed methods, this study has enabled young people with disabilities to give their perspectives on different health areas. This was particularly important and challenging in relation to sexual health. An attempt was made to develop methods that allowed participants to articulate their knowledge and understanding yet remain sensitive to the fact that some individuals may find this topic difficult to discuss. These methods could also be of utility when working with young people without disabilities, and future work should build on the approach used in this thesis. Other innovative initiatives that have been used in discussing sexual health and wellbeing with young people include the previously discussed TASC report (Morrison, 2006) and the 'Josephine Project' (Morgan, 2008). The 'Josephine Project' attempted to create a fun and accessible approach to increasing the awareness of health and sexuality issues amongst women with intellectual disabilities. Through using a life-size, anatomically correct cloth doll called Josephine, women were able to explore issues such as sex and sexuality, health and health services, rights and choices and body image. The doll included a detachable breast to educate women how to feel for lumps and a tummy that can be opened to show the main organs of the body, helping them to understand how their bodies work.

10.3.2.2 Implications for Health Education Curriculum

The quantitative data in Phase I showed that even when young people had a good grasp of key health messages, the semi-structured interviews revealed there to be substantial gaps in their understanding. It has been argued that health education often involves presenting children and young people with discrete facts about health (for example, the nutrients present in foods, physical properties of alcohol, risk and non-risk behaviours for HIV) but provide little in-depth information about the relationship between these health behaviours and their impact upon the body (Au et al., 1999; Sigelman et al., 2004). To illustrate this, even when participants with intellectual disabilities had a good understanding of what alcohol could do to the body, very few were able to articulate how it brought about these effects. Therefore, young people may have grasped different health facts from formal health education, but this does not necessarily enable them to reason and make informed choices in novel situations that have not been discussed (Au et al., 1999). It may therefore be important that young people are provided with knowledge of body systems, such as the circulatory, digestive and nervous systems, in order to provide a broader framework that helps to link pieces of knowledge together. There is evidence that providing young people from the general population with conceptually coherent information about health, including sexually transmitted diseases and drug effects, can benefit their ability to think through the consequences of their actions in different situations (Au and Romo, 1996; Sigelman et al., 1996; Zamora et al., 2006). In addition, people are better at remembering conceptually coherent information than unconnected material and it can reduce the cognitive load of having to learn a list of seemingly disjointed facts (Zamora et al., 2006). Therefore, further work is needed on how best to deliver this information to people with disabilities. It has been argued that to do this effectively, it is important to ensure that health education is linked with science curricula to enhance students' biological understanding (Keselman et al., 2004). Clearly though, people with intellectual disabilities are likely to struggle with more abstract concepts.

10.3.4 Supporting Social Support Networks

This section will draw on the current findings as well as past research to discuss how we can develop more effective strategies to promote meaningful and rewarding relationships for young people with disabilities. Data was not collected on young people's perceptions of

their social networks and how satisfied they were with them, and it is recognised that this limits the conclusions that can be drawn. As with past research, the current study demonstrated that young people with intellectual and physical disabilities had poorer social networks than their non-disabled peers, spending much of their time engaged in solitary activities within the family home. As discussed in chapter 3, much of our social, emotional and practical needs are met by informal support systems such as our friends and family. Therefore, for many of the young people in the current study, an essential part of human experience was missing from their lives and it is imperative that services offer young people with intellectual disabilities support to “develop opportunities to form relationships, including ones of a physical and sexual nature” (Department of Health 2001a, p. 81).

It has been argued that families and carers do not always recognise or prioritise the importance that friendships have for people with intellectual disabilities (McVilly et al., 2006b). As such we may need to work with families, as well as professionals to help them better understand young people’s needs and aspirations (McVilly et al., 2006a). For the young people in the current study, school holidays were of particular concern as they often resulted in extended periods of time when they did not get to see their school friends. Past research has highlighted a number of barriers to developing and sustaining friendships for people with disabilities and parental input could be vital here, especially at times of transition (leaving school or college, starting employment; McVilly et al., 2006b).

As discussed previously, an individual’s satisfaction with their social network is not only determined by the number of contacts within that network or even the frequency of engaging in social activities. Also important is what McVilly et al. (2006a) defined as the “‘emotional dimension’, arising from the person’s perceived (lack of) meaningful and rewarding socio-emotional bonding with others, on a more intimate level” (p.192). In other words, relationships need to be perceived as reciprocal. For instance, Forrester-Jones et al. (2006) reported that staff members frequently provided emotional and practical support to individuals with intellectual disabilities, but these relationships were the least likely to be described as reciprocal. It has been suggested that specialist befriending schemes may be beneficial to people with intellectual disabilities (Forrester-Jones et al., 2006) and indeed, many of the young people with disabilities who participated in this research discussed having a ‘befriender’. Although participants valued their befriender, often it was noted that these individuals were older, of the opposite sex and meetings tended to be infrequent

(fortnightly or monthly) and highly structured. It was therefore not clear how reciprocal these relationships were. In addition, negative aspects of befriending schemes have been noted, including the idea that these relationships are often 'artificial' and 'unnatural' (Hughes, 1999). Several authors have suggested that energy should be directed into strengthening existing relationships rather than compensating with more formal ones (Hughes, 1999; Llewellyn and McConnell, 2002). This may help to promote relationships that are more sustainable as they are rooted in existing and 'naturally' occurring opportunities (Hughes, 1999; Llewellyn and McConnell, 2002). To be able to achieve this, we need to understand more about the natural progression of relationships (Hughes, 1999), and it is imperative that this fits with individuals' goals and aspirations.

It has been argued that both an individual and system-level approach may be beneficial to promote the social networks of people with disabilities. In relation to the former, this may include teaching individuals the social skills required for developing and maintaining relationships (Forrester-Jones et al., 2006) or targeting personal characteristics that have been associated with developing friendships and social network size/composition, such as confidence, fear of rejection (McVilly, 2004) or adaptive or challenging behavior (Robertson et al., 2001). However, research has also highlighted the critical role of setting factors (Robertson et al., 2001) and focusing on personal characteristics is not sufficient (Emerson & McVilly, 2004). Hamlin (2004) argues that to effectively tackle the social exclusion faced by people with disabilities, this will necessitate working with local communities and helping these individuals to become active members of their community; "If people with learning disabilities become connected to and involved in their community, the opportunities for informal sources of support to develop are significant" (p.11). One approach to community development is the Scottish Human Services Trust's (SHS) initiative, *Common Knowledge* (www.ckglasgow.org.uk). Common Knowledge was established in 2000, jointly financed by the Glasgow Learning Disability Partnership and the European Social Fund. It is a partnership between people with intellectual disabilities, families, statutory and voluntary organisations, further education colleges and social inclusion partnerships. The aim of Common Knowledge is to tackle social isolation and the lack of community involvement. One project, led by a steering group of young people with intellectual disabilities from North Glasgow College, was to develop an accessible web-based resource to be used and maintained by people with learning difficulties. As well as covering topics such as relationships, peer pressure, kissing, masturbation and safe sex, the

resource provides access to an online community allowing people with intellectual disabilities to interact with each other. Common Knowledge also works with local employers to help them recruit, train and support people with intellectual disabilities (Scottish Human Services Trust, 2001). One participant interviewed in this research had helped Common Knowledge set up the 'CK Click' website (www.ckclick.org.uk). This individual is now part of the editorial team, working for Common Knowledge and devising training to help others develop their skills.

It has been argued that a key aspect of combating the social isolation faced by people with disabilities is tied to changing society's negative attitudes toward sexuality and disability (Forrester-Jones et al., 2006). There is evidence that society's attitudes are changing (Cuskelly and Bryde, 2004; Karellou, 2003), yet there is a need to continue building on the progress which has been made. One route may be through using the media to portray the sexuality of people with disabilities in a positive light (Forrester-Jones et al. 2006; Simpson et al., 2006). There are examples of such initiatives, for example Channel 4's film '*Truly Madly Deeply*' which followed five months in the lives of three people looking for romance through the dating agency for people with intellectual disabilities, 'Stars in the Skies'. However, it is important to evaluate initiatives to find out what works (Forrester-Jones et al. 2006).

10.3.5 Working with Families

Although there have been limited formal evaluations of sex education for young people with disabilities there is evidence of promising initiatives (Fraser and Sim, 2007). One example is a programme in the USA called *Responsible Choices Program* (Plunkett et al., 2002), which was designed to address some of the wider social-cultural issues relating to sexuality. This programme, in addition to providing knowledge and skills, assists family and other support persons in gaining sexuality knowledge and skills to enable them to support the young person. Research commissioned by Health Scotland to find out more about what young people with intellectual disabilities need when it comes to sexual health services also highlighted the importance of involving parents and carers (Morrison, 2006). Unfortunately, Morrison's report and the findings of the current study suggest that young people with disabilities may find it difficult to talk to their parents about sexual matters. There is evidence that frequent and positive parent-adolescent communication may be

associated with more positive sexual behaviours (fewer sexual partners, delayed and less frequent sexual activity). Moreover, involvement in sex and relationship education programmes can help increase communication between adolescents and parents (Meschke et al., 2002). Research is therefore needed to highlight the support needs of families and identify the barriers that are preventing this transmission of information.

Although parental involvement in sex education is important for all young people, it is probably more important for young people with disabilities who may have fewer alternative opportunities or avenues to learn about sexual matters. In addition, as young people may perceive others to have negative attitudes toward them discussing sexuality, topics may not always be initiated by young people themselves. Consequently, parents need to be made aware of the importance of being proactive with regards to their child's sex education and they need to be supported to do this. Allowing their child to remain ignorant about his/her body can be dangerous, and even if a parent does not address sexuality issues with their child this does not mean that the young person will not pick up facts from other sources, such as films and the television, or from verbal and non-verbal messages (Parritt et al., 2008). Parental communication can potentially have negative effects upon young people if it is biased by their own beliefs and values (Health Scotland, 2008) and parents need to be aware of this. If children and young people are not informed and prepared for the developmental changes they face as they enter adolescence, both in relation to changes to their body and their feelings/emotions, this can become a very frightening experience (Parritt et al., 2008).

It is important for health education to start from a young age, encouraging children to take an active role in their health and providing opportunities to apply this knowledge and develop skills in everyday situations (Jobling, 2001). In relation to sex education, it may be more useful to view it from a "process" perspective, where it becomes a normative part of every day life, rather than a "session" approach which might appear disjointed and meaningless. For example, there may be times when it is opportune to talk about certain topics or when young people are more willing to listen. Health education should not stop once a young person has left school or college, but information and support should be provided throughout the young person's life and this is where family support could be crucial. Ordinarily, parents seem to have limited involvement in sex and relationship education provided within their children's school (Health Scotland, 2008). Yet this

involvement needs to be greater if parents are to have confidence in what is being taught at school and the ability to reinforce these messages at home. At the same time, it is important to bear in mind that any parent might find it difficult to talk about sexual matters with their offspring. Although there are resources for parents of young people with intellectual disabilities, they may have limited knowledge of relevant services and information (Simpson, Lafferty and McConkey, 2006). Hence, a greater effort needs to be made by educational services and other professional groups to make the family aware of available materials and sources of support.

10.3.6 Formal Sex Education

Young people with disabilities in the current study relied heavily upon formal sex education. In one sense, the finding that the majority of young people reported having received health and sexuality education from school and/or college is very promising, particularly as previous research has reported that there are still some young people with disabilities in Scotland who have never been given any sex education (Morrison, 2006). However, it became apparent that as the participants had different information needs and levels of understanding, the sex education they had received was not always appropriate or retained. Young people with disabilities, as well as requiring information on sexuality in general, may need additional information on the effects of their own disability on sexuality and reproductive function (Berman, Harris, Enright et al., 1999). If such issues are not addressed, discussions may appear irrelevant to their needs (as found in this study) and as such they are unlikely to be active participants in their sexuality education (Berman et al., 1999). It is important that sex education programmes are evaluated in order to assess their effectiveness and relevance to young people. In addition, as young people with disabilities were not accessing information from friends and had fewer incidental learning experiences, they may need additional input around relationships and emotional aspects of sexuality (Townesley, 2004).

Many of the young people with and without disabilities in this study stated that they no longer received adequate information and support in relation to sexual health from their further education college. Therefore, at a time of increased freedom and with increasing significance being placed on developing relationships, when it is even more important to provide good sex education and support, such input is absent. It may be helpful to have

continuity in sex and relationship education through all the stages of education, and further research is needed to better understand and more effectively support young people as they negotiate their way through adolescence.

This study has highlighted the need to facilitate young people in accessing more formal sources of information. The finding that young people with disabilities have a more limited awareness of sexual health services has been reported elsewhere (Craik, 2002). Research has begun to identify what young people with disabilities want from sexual health services (Morrison, 2006). However, as very few young people in this study reported having accessed sexual health services, further information is needed to explore how young people's needs can be better met and how awareness of and assistance to use sexual health services can be increased (Fraser and Sim, 2007). One approach is to ensure that services are proactive rather than reactive, and this is likely to involve making links between sexual health services and schools/colleges (Fraser and Sim, 2007). This might include young people visiting clinics so they can become familiar with the services available before they need them. Empowering young people so that they know how to access specialist sexuality services on their own, and making them feel positive about using these services could help to promote more positive attitudes towards sexuality in general.

10.3.7 Implications for Health Models and Interventions

Theories and models of adolescent health behaviour are important, as they can help to guide the development of educational materials and interventions to change behaviour and aid in the evaluation of interventions (Abraham, Sheeran and Wight, 1998). Fisher and Fisher (1992) concluded that the ineffectiveness of many sexual health interventions was due to the atheoretical nature of the materials used. A review of sex and relationships education in Scottish secondary schools reported that theory-based interventions were more effective in changing attitudes and behaviour than those that were not (Health Scotland, 2008). Unfortunately models of adolescent health behaviour have not been applied to individuals with intellectual disabilities and their potential usefulness in guiding health research and interventions remains unclear.

In addition, although social cognition models, such as the Theory of Planned Behaviour (TPB, Ajzen, 1985, 1988, 1991; see chapter 4) have been successful in predicting different behaviour in the general population, particularly health promoting behaviours (Armitage

and Connor, 2001) they have been less successful at predicting risk behaviours, such as risky drinking or sexual behaviours (Gerrard, Gibbons et al., 2008). These models maintain that health behaviours are the end result of a rational decision-making process which is based upon a deliberate processing of the available information. The emphasis is on the individual's cognitive processes, and decision making is seen as a private process that occurs separately from social context. However, decision making does not occur in a social vacuum and indeed as shown in Phase II, young people with and without disabilities share social representations of the types of people who engage in risky behaviours. It may, therefore, be useful to examine the impact of these representations on young people's health related decisions, and one model which allows this is the prototype/willingness model (PWM), developed by Gibbons, Gerrard, & Lane (2003).

The PWM views behaviours such as risky drinking or sex, not as intentional, but rather a reaction to social circumstances and sees young people as being opportunistic in exploring their identities. The PWM is a dual process model which suggests that in making decisions there are two pathways to adolescent risk behaviour: i) the reasoned path, which is similar to the TRA/TPB where attitudes and subjective norms lead to behaviour via *behavioural intentions*, and ii) the 'social reaction path', which aims to capture unplanned behaviours and the social aspects of decision making. The social reaction path includes an additional proximal antecedent to behaviour, *behavioural willingness*, what Gibbons et al. described as an openness to engage in risky behaviour under certain circumstances.

According to this PWM model, the representations or prototypes adolescents hold about the type of person who engages in risk behaviours are related to their willingness to engage in risk behaviours when the opportunity arises. By engaging in that behaviour, they become associated with the attributes of that representation. For example, in the current study when participants were presented with the opportunity to accept the drink, several participants had an image of the drinker as 'irresponsible', an image that was unacceptable to them and therefore could inhibit their behaviour. The more favourable these images are and the more similar they view themselves to the risk taker, the more willing the individual is to engage in the risky behaviour. In this way, adolescents do not plan or intend to engage in behaviour, but acknowledge they may be willing in certain situations to do so. Although traditionally prototypes have been viewed as inhibitory (people do not aspire to become associated with negative images), it is clear from this and previous research that

adolescents view some risk images positively (someone who drinks is 'sociable' or 'fun') and non-risk images can be viewed negatively ('boring'). Therefore, images or prototypes can have both a facilitating and inhibitory role on health-risk behaviour (Rivis et al., 2006).

The idea that young people do not plan to engage in risky behaviours, yet may be willing to if particular situations arise has implications for education interventions. Firstly, prototypes or images are considered malleable and as such are useful target for health interventions (Blanton et al., 2001; Gibbons, Gerrard, Lane, Mahler, & Kulik, 2005; Thornton et al., 2002). For example, a drinking-delay intervention aimed at African American adolescents was effective at altering the participants' favorable views of the typical drinker of their age group (Gerrard et al., 2006). This intervention had a significant effect on their alcohol consumption, and this was maintained at a 24-month follow-up. Other research has shown that describing peers who engage in risky or unprotected sex in negative terms can lead to young people holding less favourable images about such peers, and this in turn can lead to a decreased willingness to take sexual risks (Blanton et al., 2001, Thornton et al., 2002). As prototype similarity has been shown to be a strong predictor of intentions (Rivis et al., 2006), enhancing young people's perceived similarity to abstainer images and their dissimilarity to unhealthy actor could be useful for interventions (Rivis et al., 2006).

A number of participants in the current study had no intention of engaging in risky behaviour themselves, but nevertheless had quite positive attitudes to risk taking behaviour. Gerrard et al., (2008) have argued that such permissive attitudes are often associated with 'experimentation with risk behaviours' (p. 52) and as such interventions are best targeted at an early age. They argue that helping children and adolescents to understand the difference between willingness and intention may help them consider the potential negative consequences of being in potentially risky situations and allow them to develop strategies for avoiding these situations, or could be argued, being prepared. This is of particular relevance to the current study, as participants had no intention to engage in the behaviour and as such may not have considered potential negative consequences.

Having opportunities for planning and rehearsing behaviours may help young people follow through their intentions (Gollwitzer, 1993; Gollwitzer and Oettingen, 1998). Gollwitzer (1993) propose that intentions are more likely to be enacted if they are translated into 'implementation intentions', which involves specifying when and where a

particular act is to be undertaken. Individuals can then recall these intentions more easily in the relevant situation and this leads to action more automatically. This may be particularly important for young people with disabilities who lack social scripts about drinking or sexual behaviour and for whom planning social interaction and negotiation about such topics may be more important.

10.4 Strengths and Limitations of the Study

This research makes a contribution to the evidence base about the knowledge, attitudes and experience of young people with and without disabilities in relation to a broad spectrum of health issues. The strengths of this research include the careful development and piloting of materials and methods that were suitable for both young people with and without disabilities. These methods were designed to help young people express what they did know about health matters, rather than focusing on what they did not know. Although this is important when accessing knowledge and understanding in any area, it may be particularly pertinent in relation to sexuality where factors such as embarrassment and anxiety may prevent participants' expressing their views.

A strength of this research was having three groups of young people; two of which were socially excluded. Several studies have investigated health knowledge in individuals with intellectual and physical disabilities with their non-disabled peers (Duh, 2000; McCabe, 1999; McCusker et al., 1993; Szollos and McCabe, 1995). However, no attempt was made to examine the differential impact of cognitive determinants and social and environmental factors in influencing health knowledge and attitudes across the groups. In particular, having a group of young people with physical disabilities helped to demonstrate that social exclusion plays a part in determining the private health knowledge of young people with intellectual disabilities, with regard to sexual matters.

However, there were also a number of limitations with this research and the results need to be treated with a degree of caution. Firstly, this research only offers a 'snapshot' in time and is limited to a small number of young people. Therefore it cannot be assumed to be a representative sample of young people with and without disabilities. For instance, health knowledge and experience are determined by a multitude of factors, such as gender, ethnicity, social-economic status and age, and it was not possible to sufficiently explore all

these factors in the current research. The investigation was limited to a predominately white, Glaswegian population. Moreover, given that the West of Scotland has a reputation for poor health the findings might not be transferable to the general population living outside of this region. Therefore, where comparisons and contrasts have been made between groups and with past research, it is important that these are only tentatively made. Although data was collected on the socio-economic background of individuals, this was through a brief measure based on postcodes. As the impact of deprivation upon health knowledge, behaviour and experience is well established, further data should be collected in order to explore this relationship. It may also be beneficial to use qualitative methods to explore the real impact that deprivation has on people's everyday lives and health choices, and this may benefit from being a longitudinal approach.

Previous research has shown that personality characteristics (such as attitudes towards sexuality, sexual experience) may influence an individual's decision to participate in sexual health research (Strassberg and Lowe, 1995). Therefore, personality is a factor that could potentially limit the generalisability of the findings from the present study (Strassberg and Lowe, 1995).

Another significant limitation of this study was in relation to the group of young people with physical disabilities. Locating individuals who had a physical disability but had average intelligence proved the greatest challenge. Many of these participants were recruited from a school for children with special needs, resulting in this group being significantly younger than the other two groups, which may have impacted upon the results. Age may play a significant role in the development of health knowledge, as children's reasoning and understanding in different health domains has been shown to change with both age and experience (Sigelman et al., 1995). This may be of particular importance for health behaviours that are restricted by age, for example consuming alcohol and engaging in sexual intercourse. As the opportunities to engage in these activities increase with age, one may expect knowledge to also accumulate.

There was a more general drawback to the study regarding all the young people's experience, because information was not systematically collected about their actual engagement in health behaviours. The reason for this was that the prime aim of this research was to explore young people's knowledge and understanding, and asking about such personal information may have effected participants' involvement in the study. For

example, they may have felt it necessary to give socially desirable responses or have felt too threatened to respond honestly. Nevertheless, a lack of data about how the participants actually behave limits the conclusions that can be drawn from the current research. However, future work could build upon the methods developed in this study to explore the relationship between knowledge, attitudes and behaviour.

Gender plays an important role in health and although the impact of gender on health knowledge and attitudes was explored for sexuality, it is acknowledged that this was limited in the current research. Research focusing on gender could have important implications for the delivery of health education, as gender is an important variable influencing receptiveness to interventions (Health Scotland, 2008). McCarthy (1999) argues that males and females are unlikely to require the same sex education, advice and support and such research needs to be more sensitive to these differences. In the current research there were some differences in male and female attitudes towards alcohol and sexual behaviour, emphasising the need to tailor approaches accordingly.

Although a substantial amount of time and effort was invested in developing sensitive and meaningful materials and methods, the research was conducted with young people who were able to express their thoughts and feelings (described as having a 'mild' to 'moderate' disability). Individuals with mild intellectual disabilities are more frequently the subject of such research because they have sufficient communicative abilities to express their views reliably. Much less is known about the experience and attitudes of individuals with more significant cognitive impairments. While it has been argued that for many people with severe and profound disabilities a sexual life may not be realistic (Swain and Thirlaway, 1996), they still have sexual needs and are at increased risk of abuse and exploitation. Therefore, future work should involve developing methods that allow the sexual needs of those with more severe disabilities to be assessed (Bell and Cameron, 2003).

Recruitment of subjects for school-based health research presents unique challenges (Harrington, Binkley et al., 1997), and in the current research there were numerous delays and barriers faced in recruiting young people. It was perceived that this was as a result of exploring the sensitive topic of sexuality, coupled alongside working with young people with disabilities. There were issues on multiple levels, including gaining ethical approval and authorisation from the education authorities, approval from heads of schools/colleges and individual teachers/tutors. In addition to the number of people required to authorise

the research projects, other issues had an impact upon recruitment. These included the time taken for people to complete the assessments, particularly when they clashed with other educational commitments such as examinations, course work and inspections. The barriers faced when trying to recruit young people from an educational setting should not be underestimated and these constraints limited the representativeness of the sample. Harrington et al., (1997), noted that while researchers investigating school-based health education include information about the design, methodology and analysis of their work, very few provide detailed information about their recruitment processes. This may be useful for future studies, particularly when working in a sensitive subject area and with a potentially vulnerable group of young people.

10.5 Taking the Research Forward

From the preceding discussion it is apparent that there are several ways in which this research could be taken forward. As discussed in chapter 6, the measures used in the current research were not psychometrically validated. Although there are various tools that exist to explore health knowledge and understanding in young people with and without disabilities, these did not seem adequate to meet the research aims and objectives. Whilst substantial progress was made in the development of effective methods and tools to investigate the health knowledge of young people, there was no opportunity to address any topic in depth. Thus, future work may build upon these measures and methods to develop a detailed understanding of young people's own theories in relation to particular health issues, which can then be used to inform education strategies.

This study has attempted to examine the complex relationship between social exclusion and health knowledge and attitudes. However, because it was cross-sectional it cannot illuminate causal pathways. Investigating causal relationships can only be achieved through using prospective (longitudinal) cohort studies, which will help to further our understanding of how factors such as socio-economic status, age, life context and gender interact to influence the development of health knowledge, attitudes and experience. For instance, social support networks are likely to change with time as young people enter further education, leave home, or start employment (Levitt et al., 1993). Achieving a better understanding of young people's support networks and friendships at these times of

transition should help with the delivery of more timely and effective support with regard to issues such as sexual health (Emerson & McVilly, 2004; McVilly et al., 2006a, 2006b).

Children's reasoning and understanding about health changes with both age and experience. For example, initially children may hold highly negative expectancies about alcohol, but their expectancies become more positive over the course of childhood and adolescence, as they learn that alcohol can not only be damaging to one's health, but that it can have many positive effects too. This change in expectancies may be more marked for behaviours that are age restricted, for example consuming alcohol and engaging in sexual intercourse. However, there are no studies that examine how young people with disabilities' attitudes and beliefs change with age and or/experience. It would be interesting to compare how knowledge and attitudes of young people with and without disabilities change at different developmental transitions, for example, from school to employment or further education/training, where individuals may find themselves in new social situations, meeting new people and with increased autonomy (Pavis et al., 1998). Again, longitudinal studies may help to elucidate how young people learn to be healthy or unhealthy.

Research has identified the barriers faced by gay, lesbian and bisexual people with intellectual disabilities, recognising that they may need additional support (Abbott and Howarth, 2005). In the current study, data was not collected directly on participants' sexuality, but this does not mean it was thought unimportant. It has been reported that young people with disabilities often hold negative attitudes toward being gay or lesbian, despite not knowing what these terms mean (Morrison, 2006). Therefore it would be of interest to explore further the sources of these beliefs and the support young people may need in discussing homosexuality, or in expressing their sexuality if they are gay or lesbian.

The research outlined in this thesis could be taken forward to include interviews with parents of young people with learning disabilities. People with disabilities tend to spend a longer amount of time living in the family home than non-disabled groups (Department of Health 2001) and remain more dependent upon family support when they become adults. Therefore families are pivotal in helping people with learning disabilities to combat social isolation and gain control over their lives. Yet this research has highlighted that young people with intellectual disabilities find it more difficult to talk with their families about sexual matters than their non-disabled peers. Clearly, this is likely to be a two way process,

and there is a paucity of research exploring why families find it difficult to talk about such issues with their offspring. Moreover, further exploration is needed into how parents discuss and communicate attitudes, values and information about health, in particular sexual health, to their child. Gaining an understanding of the factors that promote or inhibit family communication about sexual issues should help with the development of sensitive and effective initiatives to support families in this regard. Finally, further information is needed on the kind of information and support they want to receive from their parents.

Despite an increasing recognition of the need to support young people with disabilities' health and sexuality education, a great deal of research is still needed and there are many gaps in our understanding of health and disability. As such, we need to develop evidence-based practices that not only address knowledge, but also empower young people to become more autonomous decision makers and take greater control over their own health and sexuality.

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Appendices

Appendix A: Overview of the Main Health Surveys Reviewed

Appendix B: Information Sheet & Consent Forms

Appendix C: Section 1: Multiple-Choice Questionnaire

Appendix D: Section 2: Likert Type Scales & Social Networks Pro-forma

Appendix E: Semi-Structured Interview

Appendix F: Visual Representation of the Semi-Structured Interviews

Appendix G: Expected Outcomes & Social Goals Questionnaire & Vignettes

Appendix H: Expected Outcomes Values – Probability Tree Diagrams

Appendix A:

Overview of the Main Health Surveys Reviewed

Broad Health Surveys

The Scottish Health Survey is a cross sectional survey of a nationally represented sample of the Scottish population. The 2003 survey is the third in a series of surveys commissioned by the Scottish Executive Health Department aimed at monitoring health in Scotland. It includes questions on general health, cardiovascular disease, respiratory symptoms, eating habits, smoking, drinking, physical activity and accidents, as well as height and weight measurements. The survey report presents results for adults (n=8,148, aged 16 and over) and children (n=3,324, aged 0-15). The Scottish Health Survey was modelled closely on the **Health Survey for England**, and the first one was carried out in 1998.

Health Education Population Survey, commissioned by NHS Scotland, monitors health-related knowledge, attitudes, behaviours and motivations to change among adults in Scotland, and includes questions on physical activity, diet, smoking, alcohol, mental health and sexual health. Data collection began in 1996, and a report has been published in 2004 (NHS Health Scotland, 2004) presenting key findings and trends from 1996-2003. In May 2006 a further report was published highlighting changes since the 2004 survey. At the last survey (2005) 1822 adults aged 16-74 were interviewed.

Information Services Division (ISD Scotland). ISD is Scotland's national organisation for health information, statistics and IT services, working in partnership with a wide range of organisations, for example NHS Scotland Unified Boards, hospitals, general practitioners and voluntary organisations. They have provided information and statistics on a wide range of areas, including alcohol, pregnancy, sexual health, intellectual disabilities, drug misuse, and obesity. The majority of statistics released by ISD are published under National Statistics; a quality marker applied to certain of the UK's official statistics.

Office for National Statistics (ONS) Omnibus Survey is a multi-purpose survey based on interviews with approximately 1,250 adults aged over 16, which began in 1990. The survey, which is conducted every month, covers England, Scotland and Wales. There are a number of core questions, covering demographic information, and non-core questions, which vary from month to month. Questions have been asked on a range of topics, including contraception, drinking behaviour, Internet access, family income, transport and so forth.

The Health Behaviours School-aged children (HBSC) study. This survey is part of a cross-national study co-ordinated by the WHO European office and is carried out every four years. It includes a mandatory core protocol that each country or region must use to facilitate cross-national comparisons, including data on self-reported / subjective health and wellbeing, smoking, alcohol consumption, cannabis use, physical activity and sedentary behaviour, eating habits and body image, oral health, bullying and fighting, injuries and sexual health. The 2001/2 survey is the sixth in the series and included 35 countries and regions. The survey involves young people aged 11, 13 and 15, with the target of 1500 respondents in each age group for each country involved. Scotland, Wales and Northern Ireland joined the survey in 1992 and England 1995.

E.g. Todd J, Currie C and Smith R. (1999) Health Behaviour of Scottish Schoolchildren: Technical Report 1: Smoking, Drinking and Drug Use in the 1990s. Edinburgh: RUHBC and HEBS.

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Targeted Health Surveys

Substance Abuse	The Scottish Schools Adolescent Lifestyle and Substance Use Survey (SALUS) established by the Scottish Executive to allow a broad based approach to the monitoring of substance abuse among secondary school children in Scotland. SALUS continues the biennial series of school surveys that have been commissioned by the Scottish Executive since 1982, initially describing smoking behaviour of children aged 12-15, and since 1990 have included questions on drinking and, in 1998, drugs. In the 2004 survey, 7062 young people aged either 13 or 15 years took part in the survey.
Eating Habits	<p>National Diet and Nutrition Survey: Young People Aged 4 to 18 Years, 1997</p> <p>This survey is one of a programme of national surveys providing comprehensive cross-sectional information on the dietary habits and nutritional status of the population in Great Britain. This survey focused on young people aged between 4 and 18 years (n=2700) and includes the following modules: a seven-day weighed intake dietary record of foods consumed in and out of the home; a seven-day record of bowel movements; a seven-day record of physical activity; blood pressure and anthropometric measurements; a fasting blood sample; a spot urine sample; an oral health interview and examination. Response rate was 80% for dietary interview and 64% for full seven-day weighed intake dietary record.</p> <p>Expenditure and Food Survey (EFS); formerly National Food Survey (NFS)</p> <p>This is a continuous survey of household expenditure, food consumption and income commissioned by the Social Survey Division (SSD) of the Office for National Statistics (ONS) and by the Department for Environment, Food and Rural Affairs (DEFRA). The survey is made up of a comprehensive household questionnaire which asks about regular household bills and expenditure on major but infrequent purchases; an individual questionnaire for each adult (aged 16 or over), which asks detailed questions about their income; a diary of all personal expenditure kept by each adult for two weeks, and of home grown and wild food brought into the home (a simplified diary kept by children aged 7 to 15 years, also kept for two weeks). The survey covers 600 households and 1, 3000 people per year in Scotland (The NFS collected data from the main purchaser for 7 days).</p>
Sexual Health	National Survey of Sexual Attitudes and Lifestyles II, 2000-2001 (NATSAL) provides up-to-date information for estimating the extent of the HIV epidemic in Britain, and examines behaviour change over time in sexual health. The face-to-face interview included sections on: general health, family, learning about sex, first sexual experience, contraception, attitudes, and household classification. The self-completion questionnaire included sections on: sexual attraction and experience, heterosexual sex, homosexual sex, number of partners, sex abroad, most recent partners, paying for sex (males only), miscarriage, sexually transmitted diseases, HIV/AIDS testing, sexual problems. the survey included 11 161 British residents aged 16–44 years undertaken between 1999 and 2001



Appendix B

INFORMATION SHEET

What Young People Understand About Health

We would like to invite you to take part in a research project looking at young people's views about health. This information sheet tells you about the project.

Before you decide whether or not you want to take part, it is important for you to understand why the research is being carried out and what you will be asked to do.



Please take time to read this leaflet carefully or ask someone to read it with you. This could be a member of your family, a teacher or a support worker.

If there is anything that you do not understand or if you would like more information please contact us. The names and telephone numbers of people who would be happy to speak to you and answer your questions are on the back of this leaflet.



Take time to decide whether or not you wish to take part – talk to your friends and family about it and ask them what they think.

What will this study find out?

The aims of the study are to find out what you understand about health. This will include things like healthy eating, alcohol, contraception, and HIV/AIDS. You will also be asked who you talk to about these subjects, where you go to find out things and the kind of things you would like to know more about.

What you say in the study will be used to help other people, like you, to make sensible choices about their health.



Why have I been chosen?

You are being asked to take part in this study because we are interested in young people's views about health. We are interested in young people who go to colleges in Glasgow. We are going to speak to about 30 more people like you over the next year. Everyone who takes part will live in Scotland.

Do I have to take part?

No. It is up to you to decide whether or not to take part.

What will happen if I decide to take part in the study?

If you think you would like to take part in the study a researcher will arrange to meet you and tell you what would be involved before you finally decide. A researcher is someone who finds out information from people.



If you decide to take part in the study you will meet with a researcher two times. Each time you will be asked different questions about health. The meetings will last for about 40 minutes.

The questions asked will be to do with;

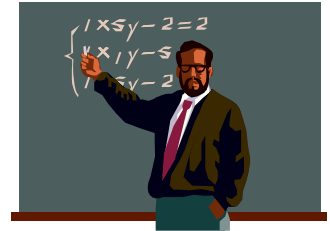
- ✓ What you know about healthy eating
- ✓ What you know about alcohol
- ✓ What you know about sexual health (i.e. safe sex)
- ✓ Who you have spoken to about these health topics
- ✓ Who you spend time with in and outside of college

Where would the interviews take place?

The researcher will arrange to see you at your college

Do I have to answer all the questions?

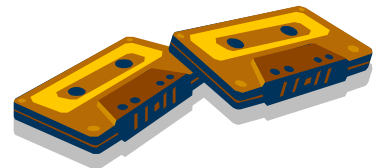
No. You can decide not to answer any of the questions if you wish.

**What if I change my mind and do not want to take part during the study?**

You can change your mind about taking part or stop at any time – you do not have to give a reason. This study is separate from your college. If you don't want to take part this will not affect any of your college activities.

Tape-recording Sessions

We would like to tape record meetings that you have with the researcher. It is up to you to decide whether or not you are happy for your meetings to be recorded. The researcher will discuss this with you at the time of your meetings – if you are not happy then no recording will be made.

**Will my taking part in this study be kept confidential?**

Anything that you say to the researcher will be private. Nothing you say will be discussed with your lecturers.

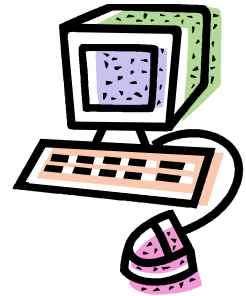
What will happen to the results of the research study?

We hope that the information we get from this study will be used to help other people like you by identifying what areas people need to know more about. The research findings will also be written into reports, which will be published. It will not be possible to identify any of

the individuals who take part in this study from reports, as all information will be anonymised (names removed).

Will I be able to find out the results of the study?

Once the research has been completed, we will invite you to a meeting where we will tell you what we have found. If you cannot make the meeting then we will send you a report written for people who took part in the study.

**Who can I contact if I want to ask questions about the study?**

You can ask as many questions as you like about the project and take as long as you need to decide whether you want to take part or not.

The following people would be happy to talk to you about the study and answer any questions:

Jaycee Pownall (Researcher on the Project)
Dept of Psychological Medicine
University of Glasgow
Glasgow

Tel: 0141 211 0221
Email: 0312777p@student.gla.ac.uk

Thank you for taking the time to read this leaflet



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of
GLASGOW**

CONSENT FORM

What Young People Understand About Health

Before you fill out this form you should have read the information leaflet that tells you about this study. The leaflet is dated October 2006. It tells you what you would be asked to do if you take part in this study.



- **Have you read the leaflet?**

YES / NO



- **Did you understand the leaflet?**

YES / NO



- **If you didn't understand something in the leaflet, did you ask someone to help you?**

YES / NO

- **Do you understand what you will be asked to do if you take part in the study?**

YES / NO

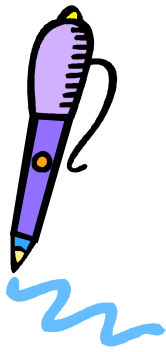
If you agree to take part in the study, you can change your mind at any time.
You do not have to give a reason.



- **Do you agree to take part in the study?**

YES / NO

Please turn over →



If you have agreed to take part you need to write your name and then put your signature below. You also need to write the date. If it is hard for you to sign your name then your teacher can witness your agreement to take part in the study.

NAME:

SIGNATURE:

DATE:

Thank you for filling in this form. You do not need to fill in any more information.

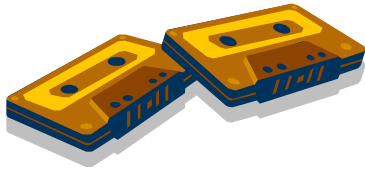
Researcher's
signature:

Date:

Participant number:



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Tape Recording the Interviews

I would like to tape record this meeting with you. Anything that you say will be kept private and I will be the only one who will listen to the tape. If you do not want me to tape the meeting that is okay. I will write down the things you say instead.

yes / no ?

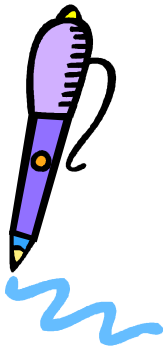
Are you happy for the interview to be tape-recorded?

YES / NO

yes / no ?

Are you happy for anything you say to be used in the final report? (It will not be possible to identify you from what you say)

YES / NO



If you have said that you are happy for the interview to be tape-recorded you need to write your name and put your signature below. You also need to write the date.

NAME:.....

SIGNATURE:.....

DATE:.....

Thank you for filling in this form. You do not need to fill in any more information.

Researcher's signature:

Date:

Participant number:

Appendix C

Section 1: Multiple-Choice Questionnaire & Participants' Responses

Healthy Eating Knowledge

Question	Response	ND n31	ID n29	PD n23
Eating lots of fatty foods is good for you?	<i>'disagree'</i>	31	28	23
Some foods help people go to the toilet regularly. Does brown bread keep you regular?	<i>'agree'</i>	31	28	23
Always adding salt to your food is bad for you?	<i>'agree'</i>	29	28	18
Which of these should you eat the most of?	<i>Fruit & vegetables</i>	21	22	16
	<i>Cheese & milk</i>	3	0	0
	<i>Meat & fish</i>	7	7	7
Which of these foods has the most sugar?	<i>Fruit & vegetables</i>	5	0	0
	<i>Biscuits</i>	26	27	23
	<i>Hot-dogs</i>	0	2	0
Which of these would make you the fattest?	<i>Bread & potatoes</i>	8	0	1
	<i>Meat & fish</i>	3	3	1
	<i>Biscuits & cakes</i>	20	26	21
Eating ONLY salad is...	<i>Very good for you</i>	2	21	3
	<i>Bad for you</i>	28	1	13
	<i>Makes no difference</i>	1	7	7
Which is the best way to cook vegetables?	<i>Steam them</i>	27	20	13
	<i>Boil them</i>	3	6	8
	<i>Fry them</i>	1	3	1

Alcohol Knowledge

Question	Response	ND n31	ID n29	PD n23
Drinking lots of alcohol can be good for your health?	<i>'disagree'</i>	31	28	23
Alcohol is like taking a drug	<i>'agree'</i>	26	14	18
People who drink too much alcohol can lose their job	<i>'agree'</i>	28	27	22
Which of these is the strongest?	<i>Vodka</i>	28	22	17
	<i>Wine</i>	3	1	0
	<i>Beer</i>	0	6	6
How old do you have to be before you're allowed to buy alcohol?	<i>15</i>	1	0	1
	<i>18</i>	30	6	22
	<i>21</i>	0	23	0
Drinking two pints of beer would...	<i>Slow down your thinking</i>	27	23	20
	<i>Would you think better</i>	0	4	3
	<i>Be just the same</i>	4	2	0
To sober up quickly you should...	<i>Drink lots of coffee</i>	4	22	11
	<i>Have something to eat</i>	15	2	6
	<i>You can't sober up quickly, you just have to</i>	12	5	6
Which would be better for you?	<i>One bottle of beer every night of the week</i>	28	18	17
	<i>7 bottles of beer on a Friday night</i>	2	4	3
	<i>Not sure</i>	1	7	3

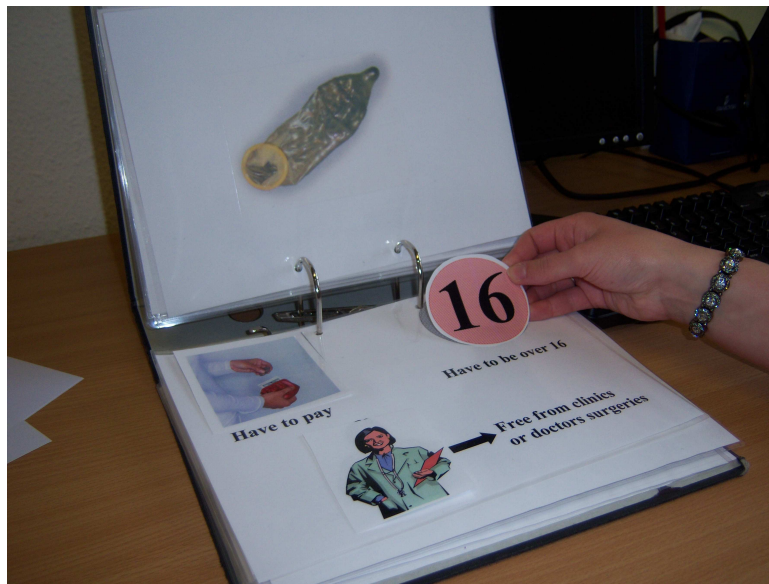
Pregnancy / Contraception Knowledge

Question	Response	ND	ID	PD
		n31	n28	n23
You have to have sex more than once to become pregnant/get a girl pregnant?	<i>'disagree'</i>	31	18	20
You should use a new condom each time you have sex?	<i>'agree'</i>	31	23	19
A man can only get a girl pregnant if he has an orgasm/comes?	<i>'disagree'</i>	22	9	8
Using a condom when you are having sex can help stop you...	<i>getting AIDS</i>	0	6	2
	<i>getting pregnant</i>	2	5	4
	<i>getting AIDS & pregnant</i>	29	15	16
	<i>getting AIDS</i>	0	0	0
Taking the contraceptive pill if you are having sex can help stop you...	<i>getting pregnant</i>	26	15	20
	<i>getting AIDS & pregnant</i>	5	8	2
	<i>You can get the oral pill from doctors surgeries or clinics</i>	28	18	17
Which of these statements about the oral pill is true?	<i>You have to be over 16 to get the pill</i>	1	7	1
	<i>You have to pay for the oral pill</i>	2	3	4
	<i>Yes that would be okay</i>	0	0	0
	<i>Yes if it its very small</i>	0	1	0
Is it okay to use a condom if it has a tear in it?	<i>No</i>	31	27	23
	<i>You always have to pay for condoms</i>	2	3	12
	<i>You have to be over 16 to get condoms</i>	1	7	8
	<i>You can get condoms free from clinics or doctors surgeries</i>	28	18	3

HIV / AIDS Knowledge

Question	Response	ND	ID	PD
		n31	n27	n23
If you catch AIDS, doctors can get rid of it	<i>'disagree'</i>	23	7	6
If you have AIDS you will catch more illnesses	<i>'agree'</i>	29	18	19
You can always tell if someone has just caught the AIDS virus	<i>'disagree'</i>	29	17	20
You are more likely to get AIDS if...	<i>You are male</i>	0	2	0
	<i>You don't keep clean</i>	0	5	3
	<i>You have sex with lots of people</i>	31	20	20
	<i>Keep healthy (eat healthily and exercise lots)</i>	1	5	3
You are less likely to get AIDS if you...	<i>Use a condom (when you have sex)</i>	30	19	23
	<i>If the man doesn't come/orgasm during sex</i>	0	2	0
	<i>You can get a vaccine to stop you getting AIDS</i>	2	11	6
Which of these statements about AIDS is true?	<i>You can take medicine to make you feel better if you get AIDS</i>	16	9	12
	<i>Nothing can be done</i>	13	7	9
	<i>Sharing a toothbrush with someone who has AIDS</i>	4	5	2
Which of these activities would most likely lead to AIDS?	<i>Kissing someone with AIDS</i>	3	11	5
	<i>Helping to wipe someone with AIDS bleeding nose</i>	23	11	20
	<i>Men who can get AIDS</i>	0	1	0
It is only...	<i>Homosexuals/gays who can get AIDS</i>	0	3	0
	<i>Everyone can get AIDS</i>	31	23	23

Section 1: Examples of visuals used during the structured Questionnaire



Appendix D

Section 2: Likert Type Scales & Participants' Responses (graphs)

Healthy Eating Beliefs

Imagine someone ate lots and lots of fruit and vegetables every day. How likely is it that...

They wouldn't get illnesses like the cold and flu

Their body would become weak and tired*

It would help keep their heart strong

They would lose their hair*

Imagine someone ate lots of biscuits/cakes/sweets everyday for many years. How likely is it that...

They would get bad teeth

They would get fat

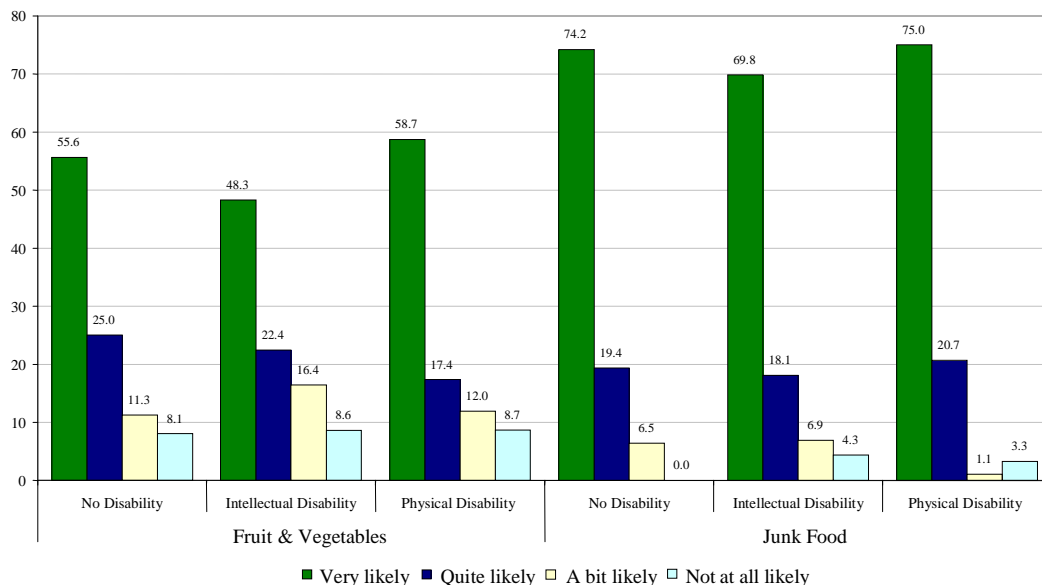
They would live longer*

They would have good skin*

** Scores were reversed*

Healthy Eating Scale:

Fruit & Vegetables and 'Junk' Food – Percentage of all responses coded at each category



Alcohol Beliefs

Imagine someone drank lots of alcohol everyday for many years. How likely is it that...

They wouldn't get illnesses like the cold and flu*

It would help then remember things*

They would get mouth disease

They would get liver disease

Imagine someone went to a party one night. They drank lots of alcohol. How likely is it that...

Alcohol gives you more energy*

They would be sick/vomit

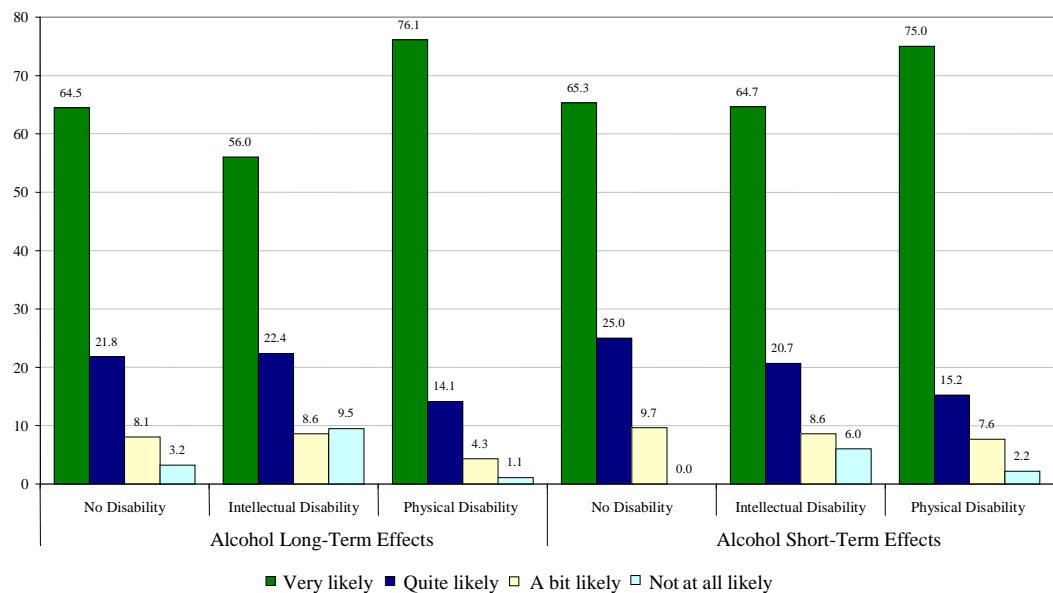
They would be able to drive better*

They would get a spinning head

** Scores were reversed*

Alcohol Scale:

Long-Term and Short-Term Effects - Percentage of all responses coded at each category



Pregnancy / Contraception Beliefs

I am going to show you some pictures. I want you to tell me how likely you think that someone would get pregnant this way. How likely is it that a man could get a girl pregnant/ a girl would become pregnant...

The first time she has sex

She has sex during her period

She has sex and her partner uses a condom*

She has sex is taking the contraceptive pill*

She has sex and washes her private parts afterward

She and her partner were deep kissing*

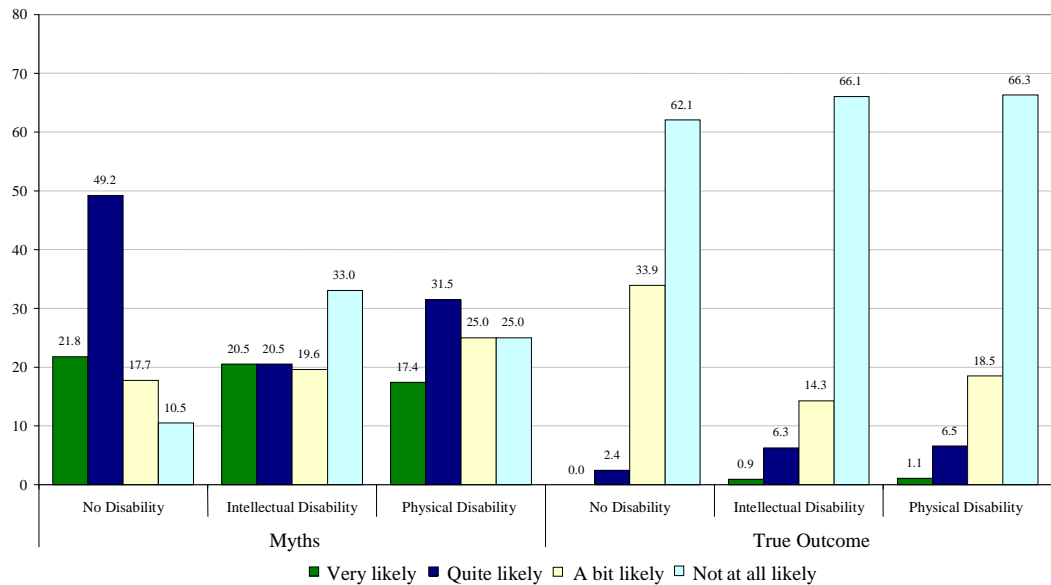
She has sex standing up

She has sex and is on the contraceptive injection*

* Scores were reversed

Pregnancy / Contraception Scale:

Long-Term and Short-Term Effects – Percentage of all responses coded at each category



HIV / AIDS Beliefs

I am going to show you some pictures. I want you to tell me how likely you think that someone would get AIDS by doing that. How likely is it that they would get AIDS if...

They kissed someone with AIDS *

Shared a needle with someone who had AIDS

Touched someone with AIDS cut

From an insect bite *

They hugged someone with AIDS *

They had unprotected sex with someone with AIDS

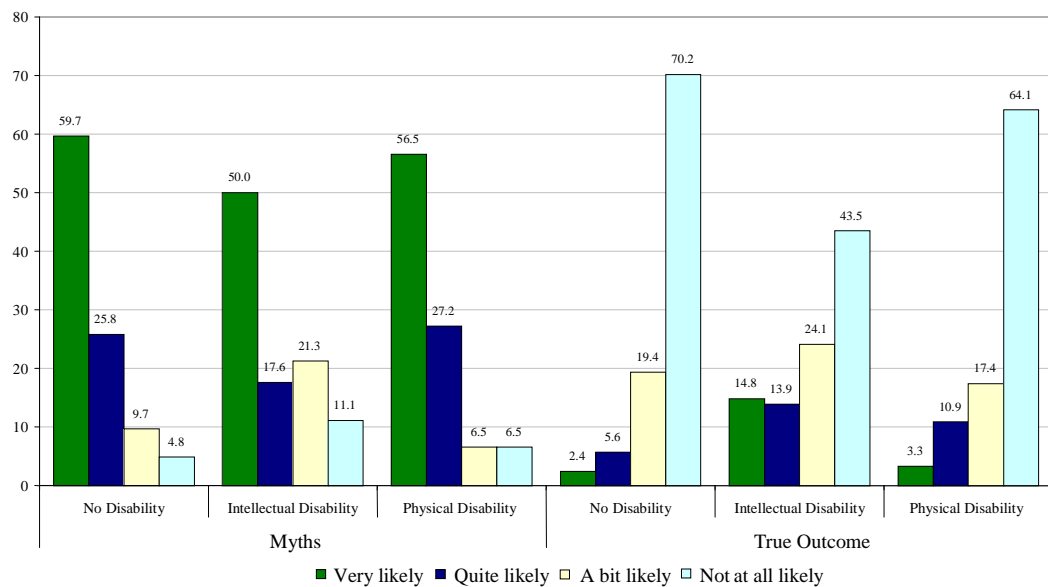
They shared a swimming pool with someone with AIDS *

(How likely would it be that) a mother could give it to her baby

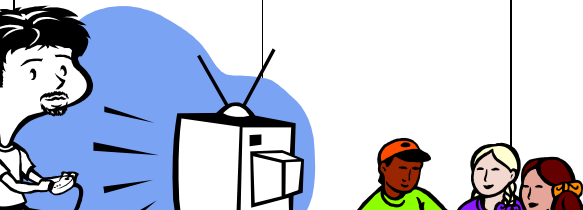
** Scores were reversed*

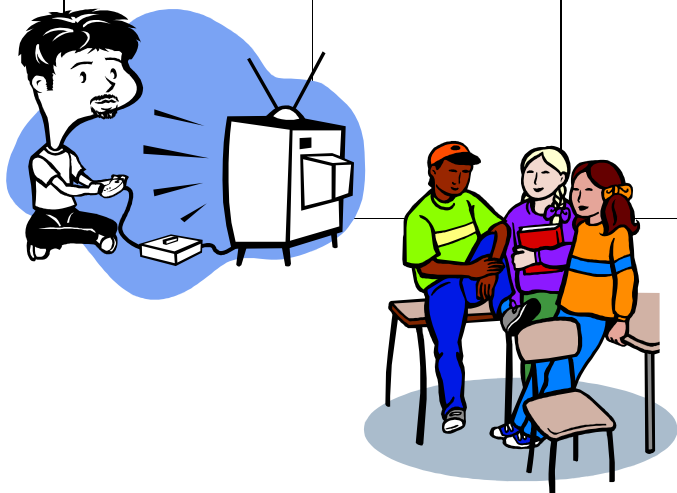

HIV / AIDS Scale:

Myths and True Outcomes – Percentage of all responses coded at each category



Social Networks Pro-forma

Monday	Tuesday`	Wednesday	Thursday	Friday	Saturday	Sunday
<p>Example Prompts:</p> <p><i>What do you usually do on (day of the week)?</i></p> <p><i>Who do you see during the day? (i.e. at break and lunch periods at school/college)</i></p> <p><i>Tell me about your friends?</i></p> <p><i>What things do you do with (named person(s))?</i></p> <p><i>How do you get home?</i></p> <p><i>Tell me about what you do when you get home/after school/college?</i></p> <p><i>What do you do at the weekends?</i></p>						
						



Appendix E

Semi-Structured Interview

Healthy Eating Questionnaire

Try to find out whether or not the respondent is aware of what kind of foods should be included in a healthy diet and which are foods should be limited. What is the reasoning behind the participant's beliefs?

Self-generated responses: Through the spontaneous definitions of a healthy diet and the consequential health effects offered by the participant, the most salient beliefs held can be explored. This will focus on the *general* effects of a (un)healthy diet.

- ☐ Opening gambit: Tell me about the foods you like to eat. What foods do you not like? *(This is also useful to make sure respondents in later sections are not simply choosing foods they like the most, as opposed to the most healthy/unhealthy)*
- ☐ Understanding of a healthy diet: What foods do you think are good for you/what foods do you think you should try to eat? What foods do you think are bad for you/ you should not eat?
- ☐ Understanding of health effects: What do you think would happen to someone if ate lots of these foods (reiterate examples of healthy foods provided by participant, for example, what do you think would happen to someone if you ate lots of fruit and vegetables?) What do you think would happen to someone's body if they ate a lot of these (Rephrase as what would happen to someone's body if they eat to little of these foods?) Repeat for unhealthy foods.

Structured responses: Try to find out if the participant is aware of what foods constitute a healthy diet from a list of popular foods. Again, what is the reasoning behind their choices? This section differs from the above in that through the provision of photographs of foods that form the major food groups, the participant is given a chance to discuss other nutrients they may not have thought of in the open-ended question. It will also allow the participant's knowledge of current dietary recommendations to be explored. *The pictures of foods will represent an example from each of the food groups, rather than specific nutrients (i.e. meats, dairy, bread, fats and sugars)*

- ☐ Sort task: Healthy or unhealthy foods: I want you to imagine that this person (outline of human body) is trying to be healthy. I am going to show you some pictures of foods. Can you put the foods you think he/she should try to eat under the thumbs up picture? (Foods that are good for him/her?) Can you put the foods you think he/she should not eat under the thumbs down picture (foods that are bad for him/her)?_What is good/bad about (named food)?
- ☐ Health affects: Imagine this person (outline of human body) ate lots and lots of (nutrient named above). What do you think might happen to them? Where would it affect in the body? Can you place a cross where you think would be affected? What is that called? What would it do to that part of the body? Do you know why?
- ☐ Can you think of anywhere else in the body that would be affected? What else might happen to someone if they ate lots and lots of (nutrient named above)?

Alcohol Knowledge

Try to find out whether or not the respondent is aware of how alcohol can affect the body and behaviour. What is their reasoning behind these beliefs?

Self-generated responses: Through the spontaneous explanations of what drinking alcohol does to individuals (including both affects on the body and changes in behaviour, in the short- and long-term), the beliefs most salient to the participant can be explored.

- ☐ Opening gambit: Have you ever tried alcohol? Did you like it? What's your favourite drink? If not, is that because you don't want to? Can you tell me why?
- ☐ Understanding of the behavioural effects of alcohol: Some people like to drink alcohol. Can you think of some things that alcohol does that would make you feel good? Do you know why alcohol would (named effect)? Can you think of ways alcohol would make you feel bad? Do you know why alcohol would (named effect)?
- ☐ Understanding of health effects: Imagine this person (show outline of human body) drank lots and lots of alcohol. Where do you think it would affect first in the body? Can you place a cross where you think it would affect? What do you think it would do to (named part)? Where would it affect next in the body? What would it do to that part of the body? Do you know why? Can you think of anywhere else in the body that would be affected? What else might happen to someone if they drank lots and lots of alcohol?

Structured responses: Try to find out if the participant is aware of what drinking alcohol does to individuals (including both affects on the body and changes in behaviour, in the short- and long-term). Again, what is the reasoning behind their choices? This section differs from the above in that through providing illustrations of behaviours, the participant is given a chance to discuss other behaviours they may not have thought of in the open-ended question. This will also give an opportunity for the participant to talk about other body parts implicated in the behaviours (i.e. the role of the brain in causing dizziness) that may not have been mentioned previously.

- ☐ Sort task: Behaviours: Here are some pictures of things that might happen to someone if they drank lots of alcohol. Some are right. Some are wrong. Can you tell me which you think would happen? If you think they would happen can you put them under the thumbs up picture? If you think they would not happen, can you place them under the thumbs down picture? Can you tell me more about that?

Pregnancy & Contraception Questionnaire

Try to find out what the participant understands about how pregnancy happens and how can it be prevented. What contraceptives have they heard of and are they are aware of how they are used/work?

Self-generated responses: Through the spontaneous explanations of how pregnancy occurs and how it can be prevented offered by the participant, not only can their beliefs be explored, but also their misconceptions and areas where they lack knowledge.

- ☐ Understanding of pregnancy: Can you tell me how someone would get pregnant/make a baby? If reply they have sex; What happens when someone has sex? What body parts does it involve? Can you point on this picture? *Outline of male and female human body.* Do you know what that is called? And then what happens? (Use visual stimuli)
- ☐ Understanding of contraceptives: Imagine two people wanted to have sex. What could they do to stop making babies/ getting pregnant? What should they do? What could they use? What else could they use? Have you heard of contraceptives? What are they? Can you name any?

Structured responses: Try to find out if participants are aware of how pregnancy would occur and how it could be prevented. This section differs from the above in that through providing illustrations and examples of behaviours that may/may not lead to pregnancy, the participant moves away from simply naming contraceptives to explaining how they would prevent pregnancy, revealing their deeper conceptual understanding.

- ☐ Sort task: Pregnancy and contraceptives: I am going to show you some pictures. Some people believe you can get pregnant in this way. I want you to tell me if you think you would get pregnant if... (*...having sex using the condom; having sex using the contraceptive/ oral pill; having sex using the contraceptive injection; having sex whilst the female is menstruating/ on her period; the first time you have sex; using the morning after pill; if the man doesn't have an orgasm/come*).
- ☐ Knowledge of pregnancy and contraceptive use: How/why would you/you not get pregnant if you (above behaviours)/How does it work? How would it prevent someone getting pregnant? / How would it lead to someone getting pregnant? For contraceptive: who would use this? How do you use (contraceptive)? Where does it go? *Show illustration of male and female human body.* When should it be used?

AIDS Questionnaire

Try to find out what the participant understands about what AIDS is and how it can be prevented. Which behaviours do they believe to be risky and their reasoning behind these beliefs?

Self-generated responses: Through the spontaneous explanations of what AIDS is and how it is transferred, again the participants beliefs can be explored, and also their misconceptions and areas where they are lacking knowledge.

- ☐ Opening gambit: Have you heard much about AIDS? have you talked about it at school?
- ☐ Understanding of AIDS: What is AIDS? What does it do to the body? Where would it affect in the body? *Use outline of human body.*
- ☐ Understanding of transmission: How would someone get AIDS? How would it get from one person to another?

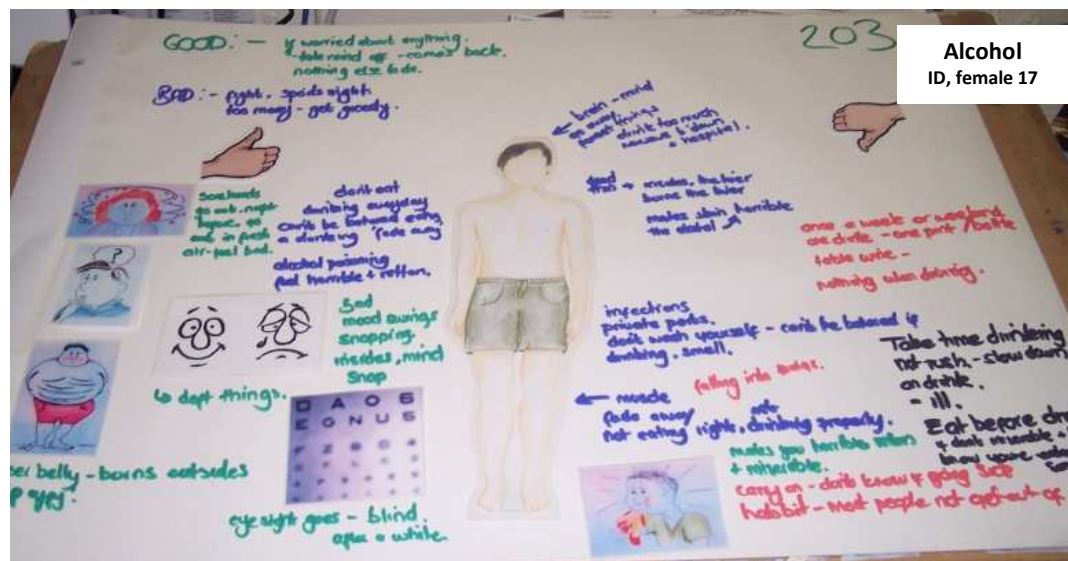
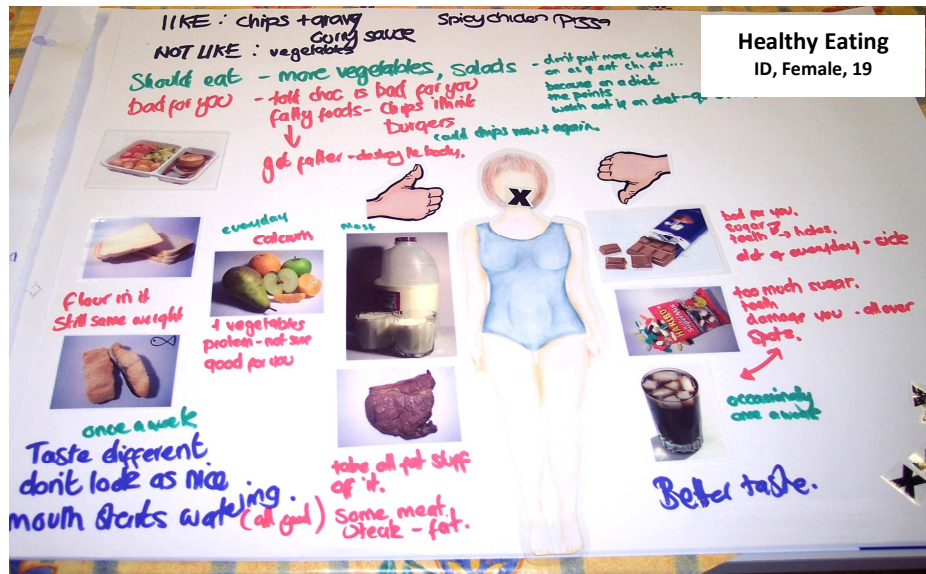
Structured responses: this tap into deeper understanding of ways prevent AIDS highlight myths. Differs as above basic this more in-depth. How catch it

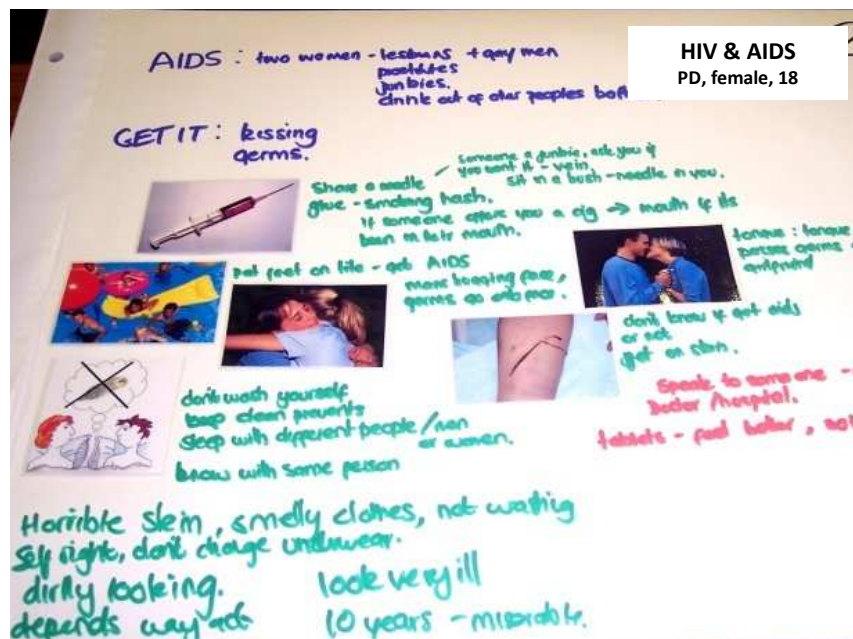
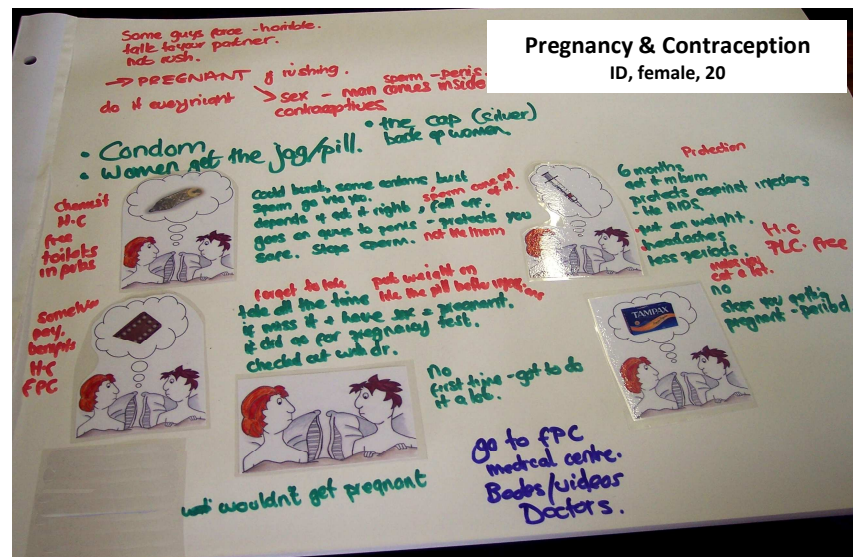
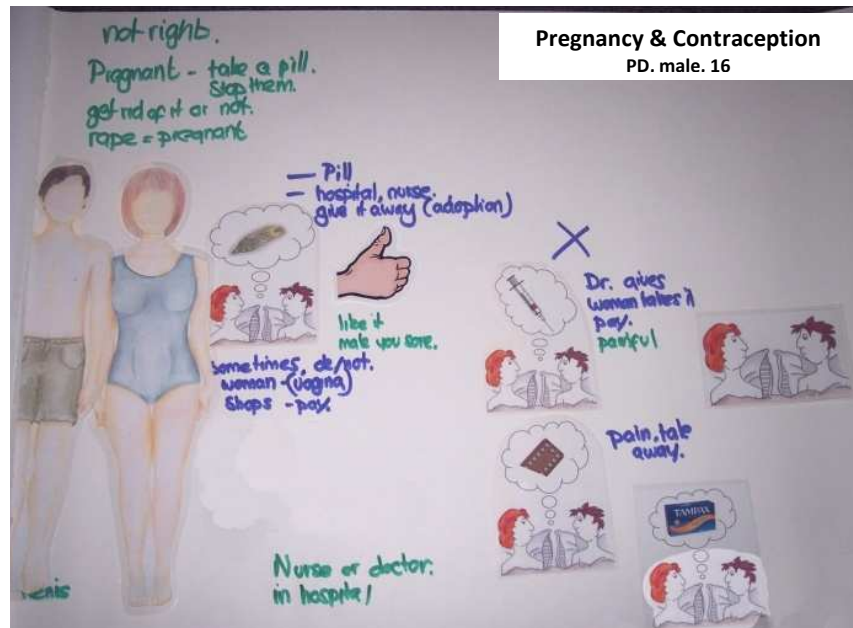
Try to find out if participants are aware of how AIDS is transmitted and how it could be prevented. This section differs from the above in that through providing illustrations and examples of behaviours that may/may not lead to AIDS, the participant moves away from simply naming positive ways of getting AIDS to stating ways which someone cannot get AIDS. By explaining how these would/would not cause AIDS will also allow their deeper conceptual understanding as well as misconceptions to be explored.

- ☐ Sort task: Risk- and non-risk behaviours: I am going to show you some pictures. Some people believe you can get AIDS in this way. I want you to tell me if you think you would get AIDS if... (*Show illustration of: having unprotected sex (what if they only had sex with each other?); touching infected blood; sharing a needle; sharing a swimming pool; hugging someone; kissing someone*).
- ☐ Knowledge of transmission and prevention: How would you/you not get AIDS if (above behaviours)? If it was a risk-behaviour; how could you prevent getting AIDS if you were to (behaviour)?

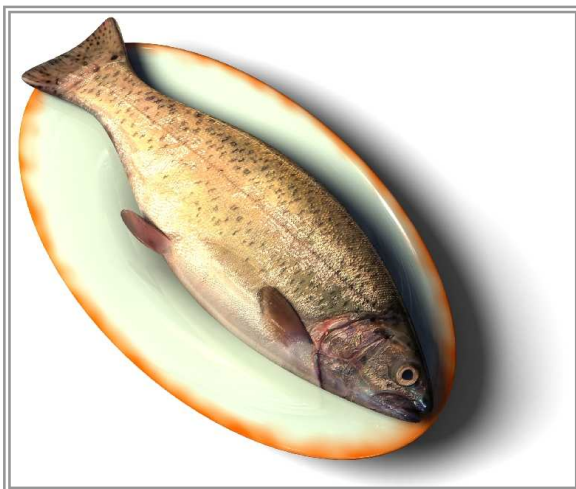
Appendix F

Examples of visuals used during the card sort-activities

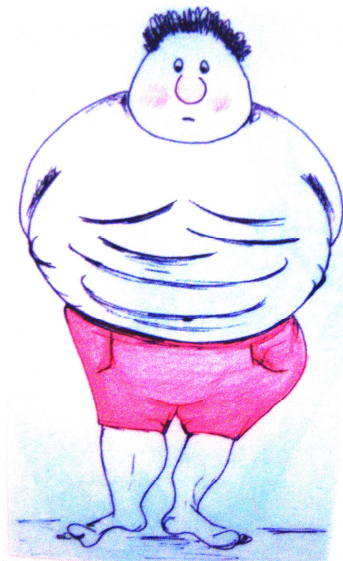




Healthy eating – Examples of Visual Stimuli



Alcohol Knowledge – Examples of Visual Stimuli



Pregnancy & Contraception – Examples of Visual Stimuli



HIV / AIDS – Examples of Visual Stimuli



Appendix G

Expected Outcomes & Social Goals: Questionnaire & Vignettes

Alcohol-Related Behaviour

Your friend is going to a party and invites you to go with them. You don't know anyone else who is going, but you decide to go to the party.



Photo 1

When you get to the party there are lots of people your age (**photo 1**). They are drinking alcohol and are having a good time.



Photo 2

Imagine that you have been at the party for a while and you have had quite a few drinks (**photo 2**). You begin to feel a bit drunk/dizzy. Other people at the party are quite drunk as well.



Photo 3

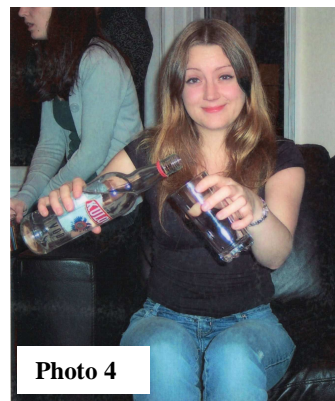


Photo 4

You start talking to a group of people at the party (**photo 3**). One of the people in the group offers you another drink (**photo 4**).

Accepting the Drink – “Imagine that you say you **TAKE another drink”**

Open-Ended: What would the **other people** at the party think about you if you took another drink?

Forced-Choice: When you took another drink would the other people at the party;

- a) Like you more and want to talk to you more
- b) Ignore you and not want to talk to you
- c) Or would they not be bothered?

Value: If the people at the party _____ (response chosen) _____, how much would that matter to you?

It would matter a lot/ a little bit/ not at all

Open-Ended: What would your **parents** say if you took another drink?

Forced-Choice: When you took another drink, would your parents say that you did;

- a) The right thing
- b) The wrong thing
- c) They wouldn't say anything?

Value: If the people at the party _____ (response chosen) _____, how much would that matter to you?

It would matter a lot/ a little bit/ not at all

Open-Ended: What would your **(close) friends** (at college) think about you if you took another drink?

Forced-Choice: When you took another drink would your close friends;

- a) Ignore you and not want to talk to you
- b) Or would they not be bothered?
- c) Like you more and want to talk to you more

Value: If the people at the party _____ (response chosen) _____, how much would that matter to you?

It would matter a lot/ a little bit/ not at all

Refusing the Drink - “Imagine that you say you **DON'T WANT another drink”**

As above, but if participant says they didn't want another drink.

Social Goals

Imagine that you were in this situation (re-read the scenario). Can you tell me what you would do? Imagine that it is completely up to you, your parents will not find out what you do. Your friends and the people at the party won't find out.

Can you tell me why you would do that?

If you did that, how would it make you feel?

Risky Sexual Behaviour

Your friend is going to a party of some people he/she knows. Your friend invites you to go with them. You don't know anyone else who is going, but you decide to go to the party.



Photo 1

When you get to the party there are lots of people your age (**photo 1**). They are chatting to each other and having a good time.



Photo 2



Photo 3

Some of the guys and girls are kissing (**photo 2**).

You start chatting to this guy/girl you have not met before (**photo 3**).



Photo 4

Some of the couples begin to leave together (**photo 4**). You have been chatting to him/her all evening. The guy/girl asks if you will go back to their house so the two of you can be alone. You have never been back to his/her house before.

Leaving with the Character - "Imagine that you say **YES** and leave with the guy/girl"

Open-Ended: What would the **other people** at the party think about you when you leave with the guy/girl?

Forced-Choice: When you leave with the guy/girl would the other people at the party;

- a) Like you more and want to talk to you more
- b) Ignore you and not want to talk to you
- c) Or would they not be bothered?

Value: If the people at the party _____ (response chosen) _____, how much would that matter to you?

It would matter a lot/ a little bit/ not at all

Open-Ended: What would your **parents** think about you when you leave with the guy/girl?

Forced-Choice: When you leave with the guy/girl, would your parents say that you did;

- a) The right thing
- b) The wrong thing
- c) They wouldn't say anything?

Value: If the people at the party _____ (response chosen) _____, how much would that matter to you?

It would matter a lot/ a little bit/ not at all

Open-Ended: What would your **(close) friends** (at college) think about you when you leave with the guy/girl?

Forced-Choice: When you leave with the guy/girl would your friends;

- a) Ignore you and not want to talk to you
- b) Like you more and want to talk to you more
- c) Or would they not be bothered?

Value: If the people at the party _____ (response chosen) _____, how much would that matter to you?

It would matter a lot/ a little bit/ not at all

Open-Ended: What would the **guy/girl** think about you when you leave with them?

Forced-Choice: When you leave with the guy/girl, would he/she;

- a) Like you more and want to talk to you more
- b) Ignore you and not want to talk to you
- c) Or would they not be bothered?

Value: If the people at the party _____ (response chosen) _____, how much would that matter to you?

It would matter a lot/ a little bit/ not at all

Refusing to leave with the character - "Imagine you that you say you DON'T WANT to leave with the guy/girl"

As above, but ask participant to imagine they don't leave with the character.

Social Goals

Imagine that you were in this situation (re-read the scenario). Can you tell me what you would do? Imagine that it is completely up to you, your parents will not find out what you do. Your friends and the people at the party wont find out.

Can you tell me why you would do that?

If you did that, how would it make you feel?

Appendix H: Expected Outcomes Values – Probability Tree Diagrams

Figure 10.1: Probability tree diagrams for value placed on expected evaluations for *accepting* the alcoholic drink - No Disability Group

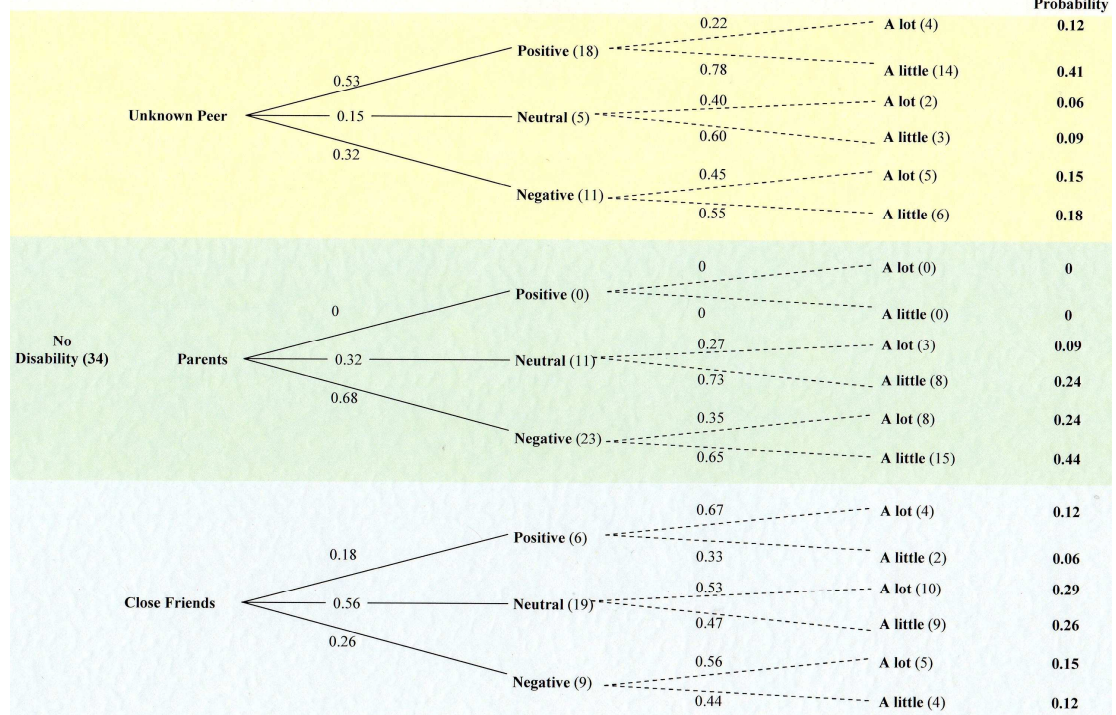


Figure 10.2: Probability tree diagrams for value placed on expected evaluations for *accepting* the alcoholic drink - Intellectual Disability Group

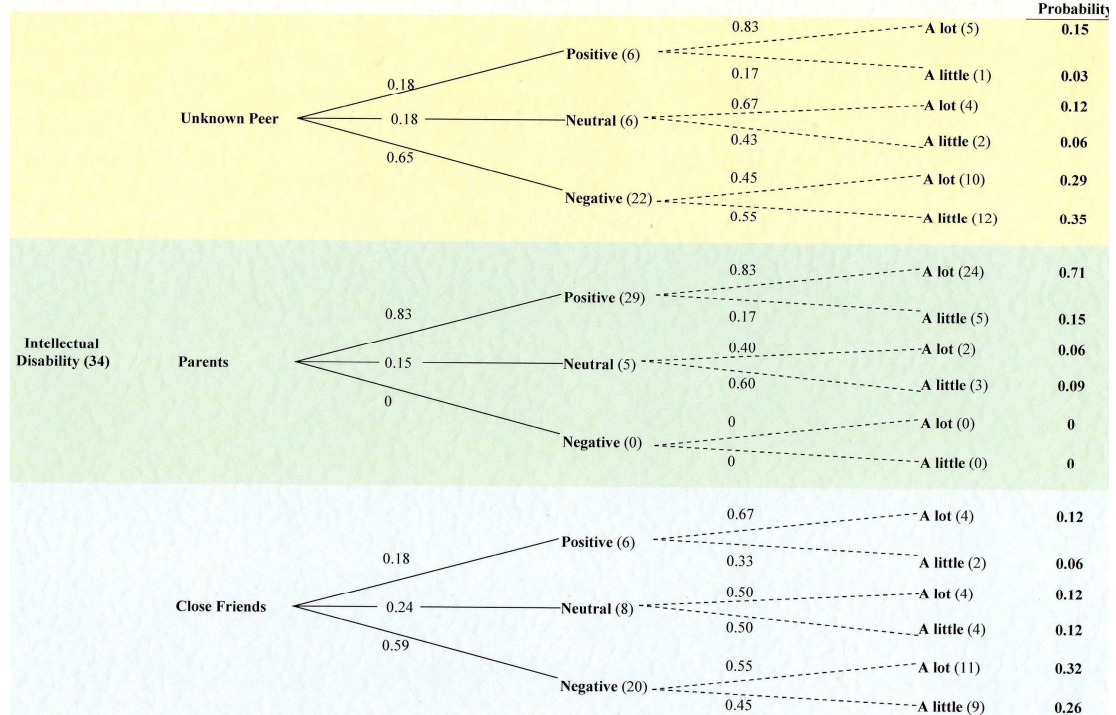


Figure 10.3: Probability tree diagrams for value placed on expected evaluations for *accepting* the alcoholic drink – Physical Disability Group

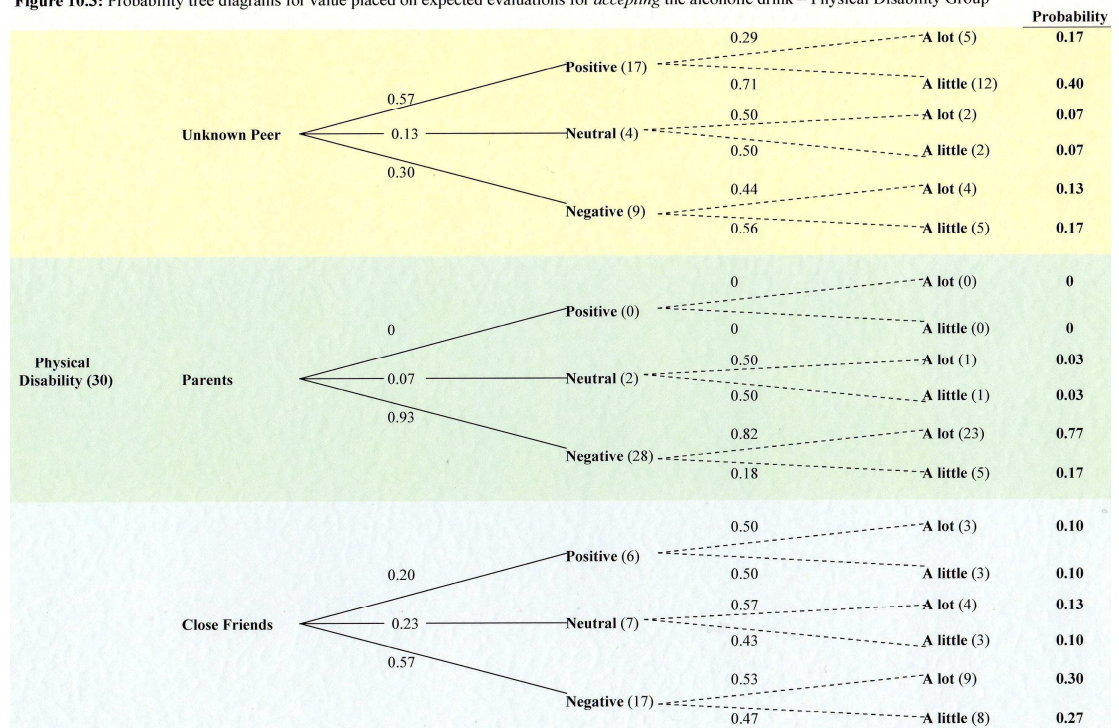


Figure 10.4: Probability tree diagrams for value placed on expected evaluations for *refusing* the alcoholic drink - No Disability Group

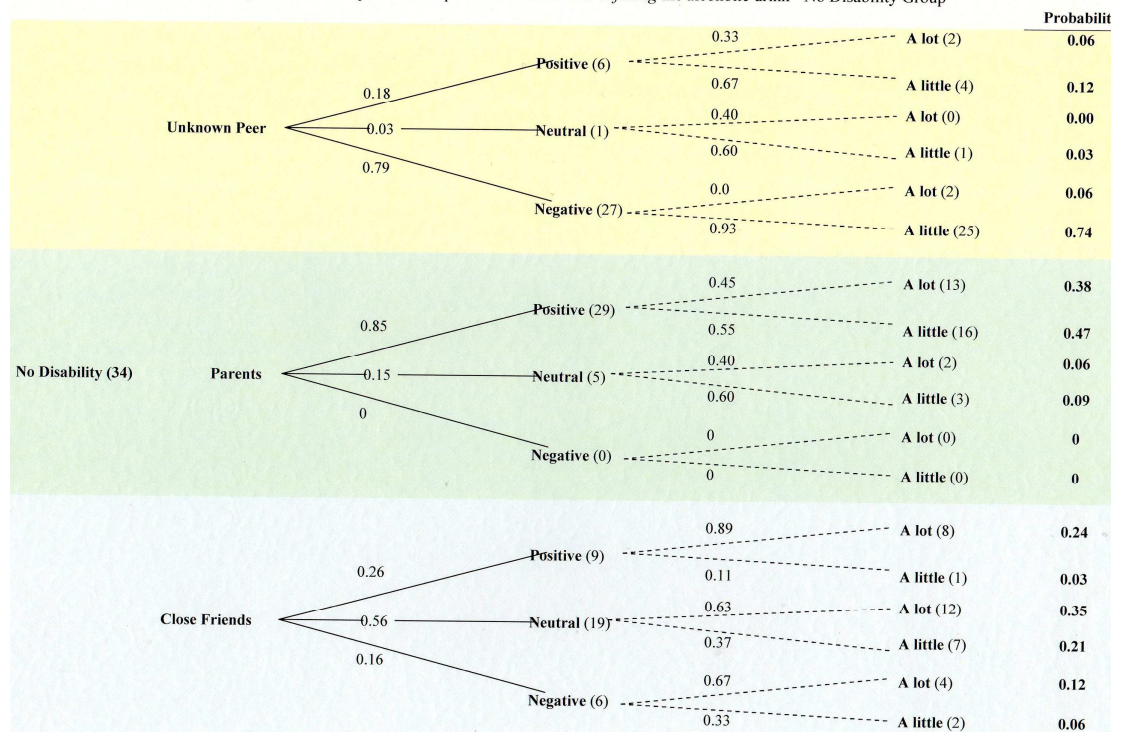


Figure 10.5: Probability tree diagrams for value placed on expected evaluations for *refusing* the alcoholic drink - Intellectual Disability Group

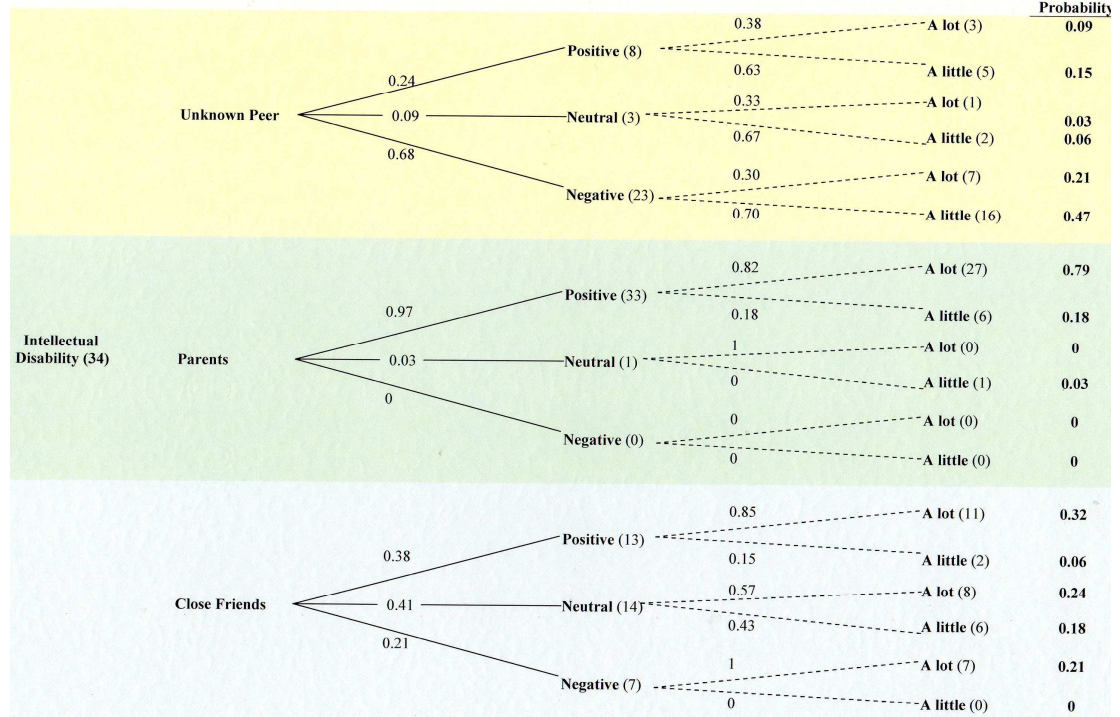


Figure 10.6: Probability tree diagrams for value placed on expected evaluations for *refusing* the alcoholic drink – Physical Disability Group

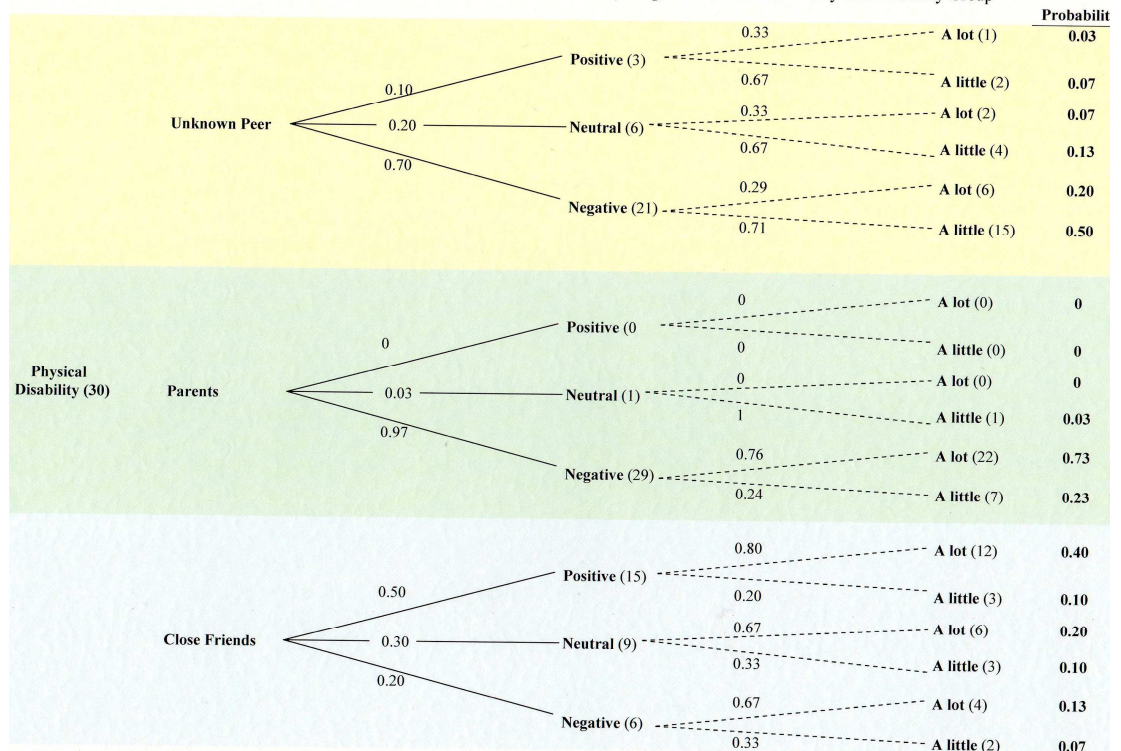


Figure 10.7: Probability tree diagrams for value placed on expected evaluations for *leaving* with the character– No Disability Group, males

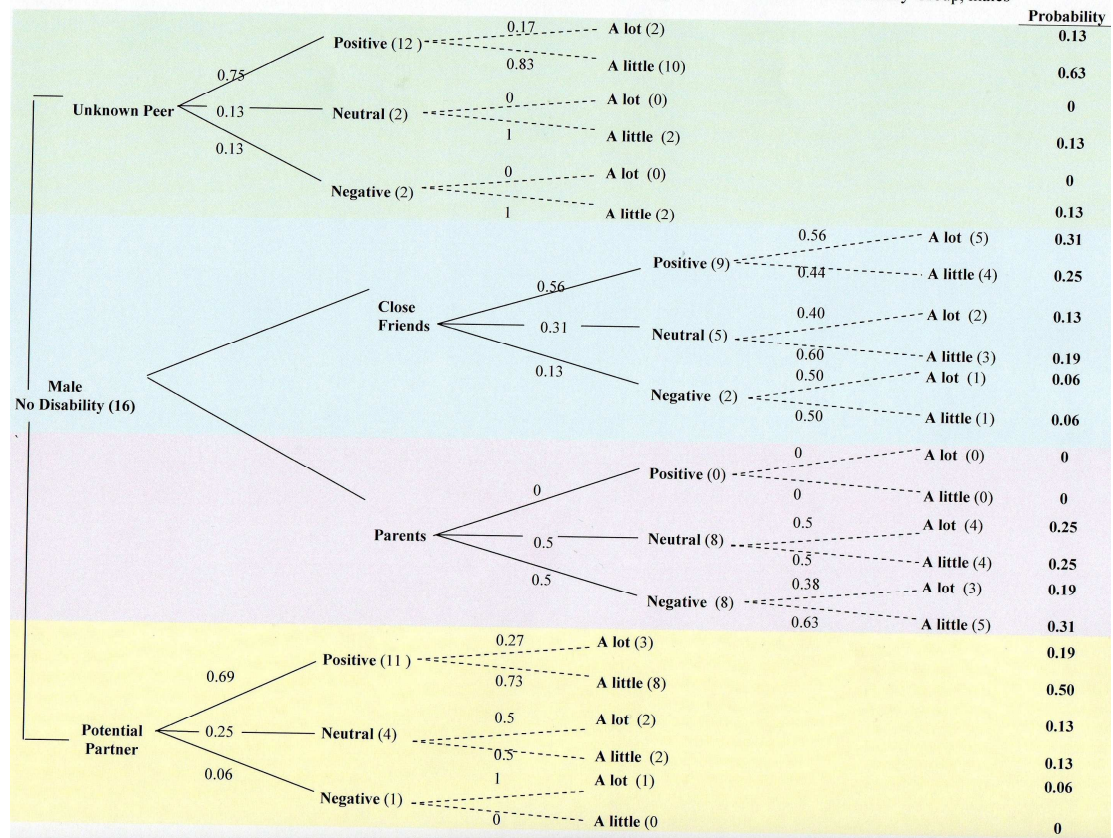


Figure 10.8: Probability tree diagrams for value placed on expected evaluations for *leaving* with the character– No Disability Group, females

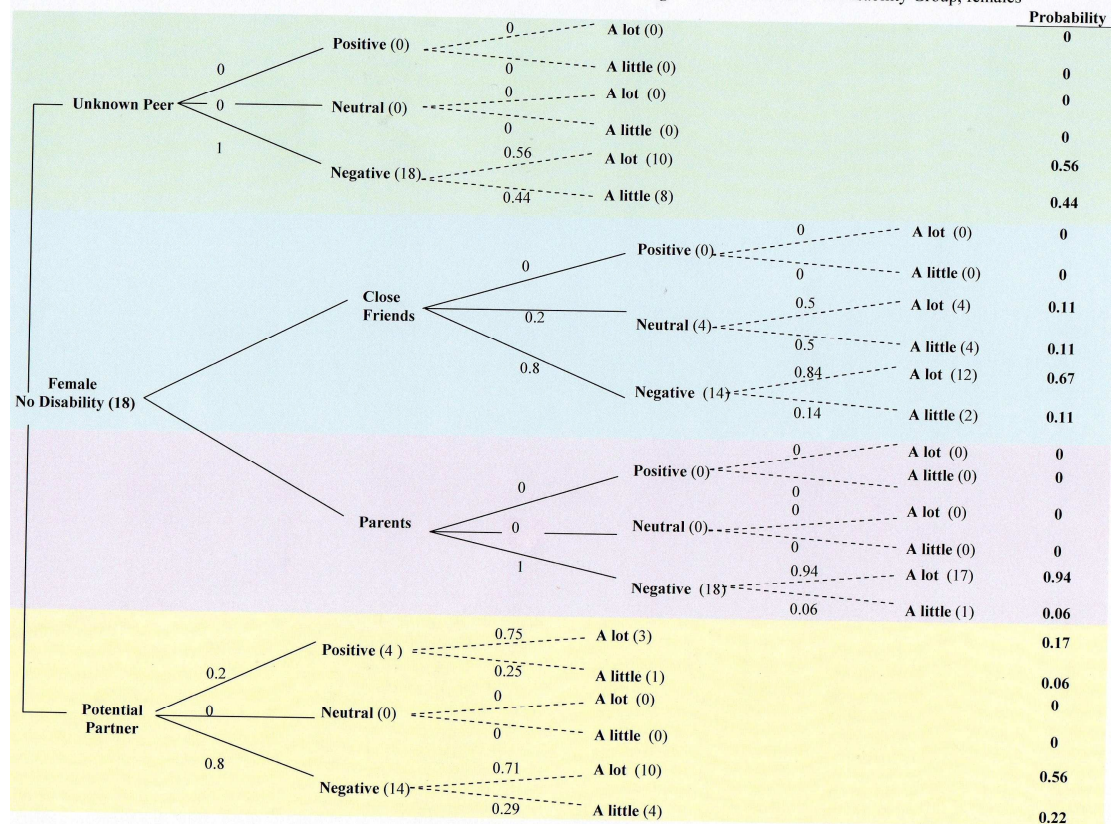


Figure 10.9 Probability tree diagrams for value placed on expected evaluations for *leaving* with the character– Intellectual Disability Group, males

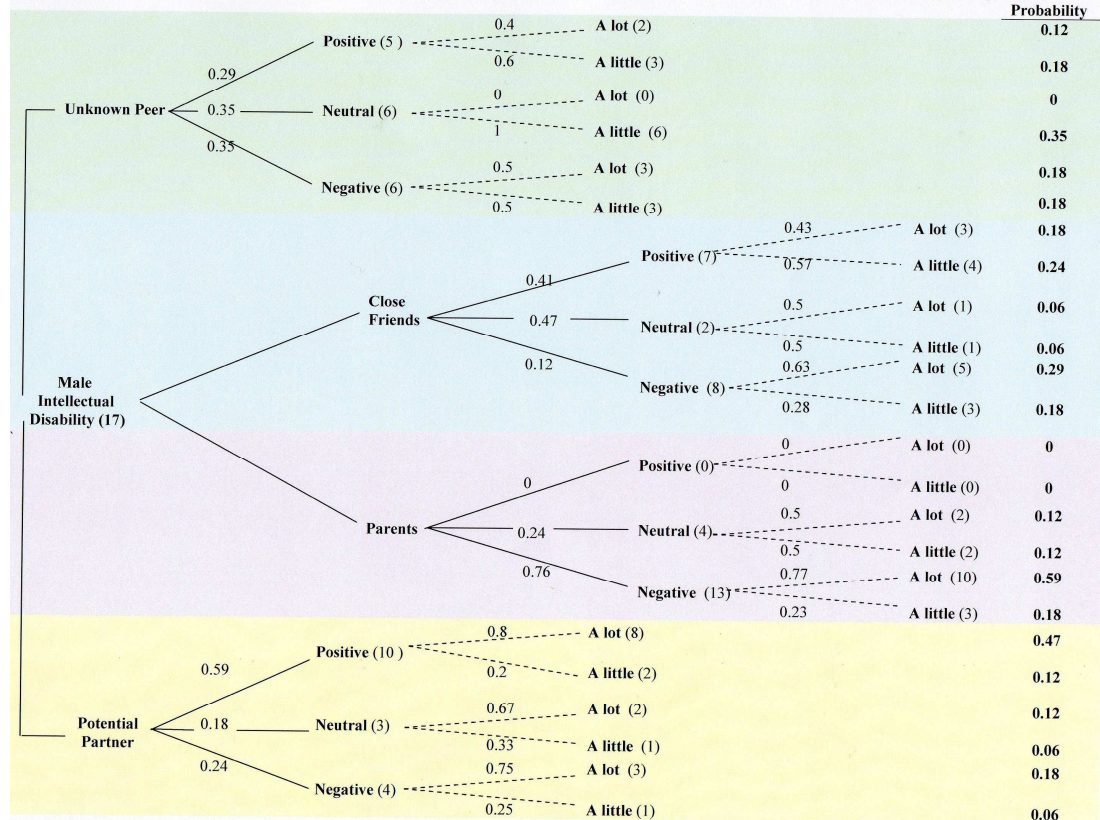


Figure 10.10: Probability tree diagrams for value placed on expected evaluations for *leaving* with the character– Intellectual Disability Group, females

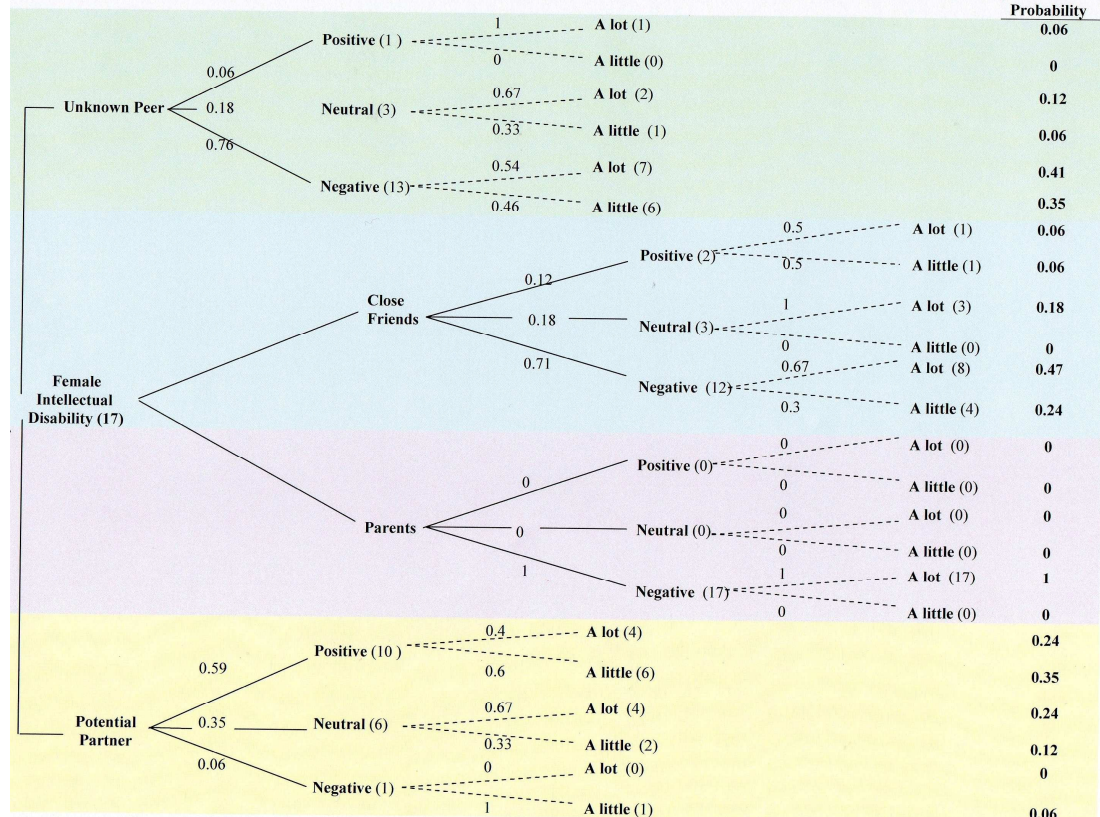


Figure 10.11: Probability tree diagrams for value placed on expected evaluations for *leaving* with the character– Physical Disability Group, males

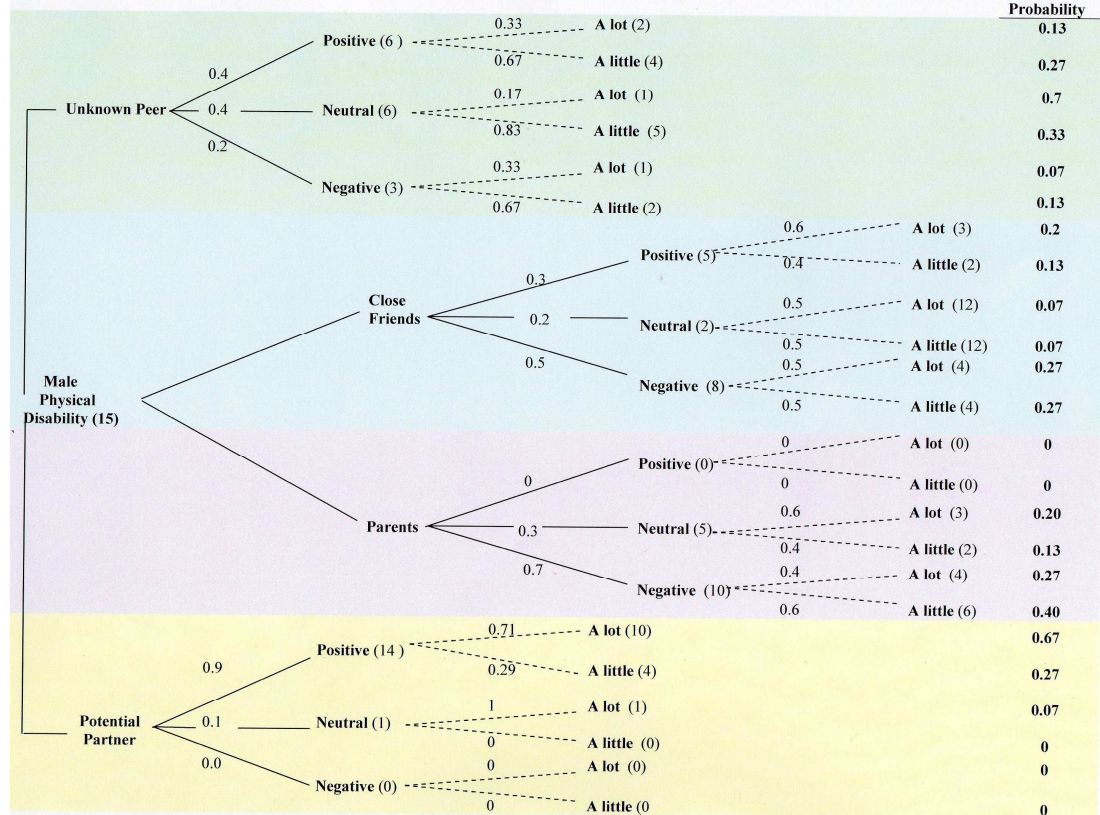


Figure 10.12: Probability tree diagrams for value placed on expected evaluations for *leaving* with the character– Physical Disability Group, females

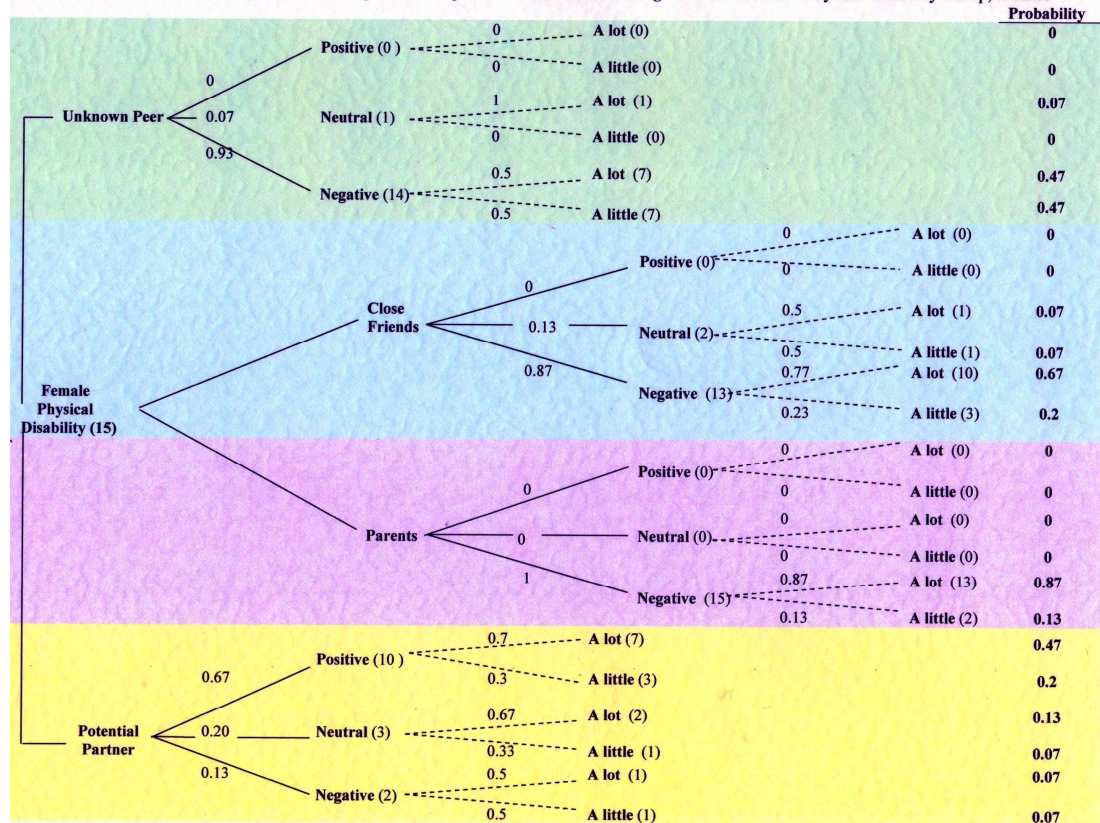


Figure 10.13: Probability tree diagrams for value placed on expected evaluations for *NOT leaving* with the character– No Disability Group, males

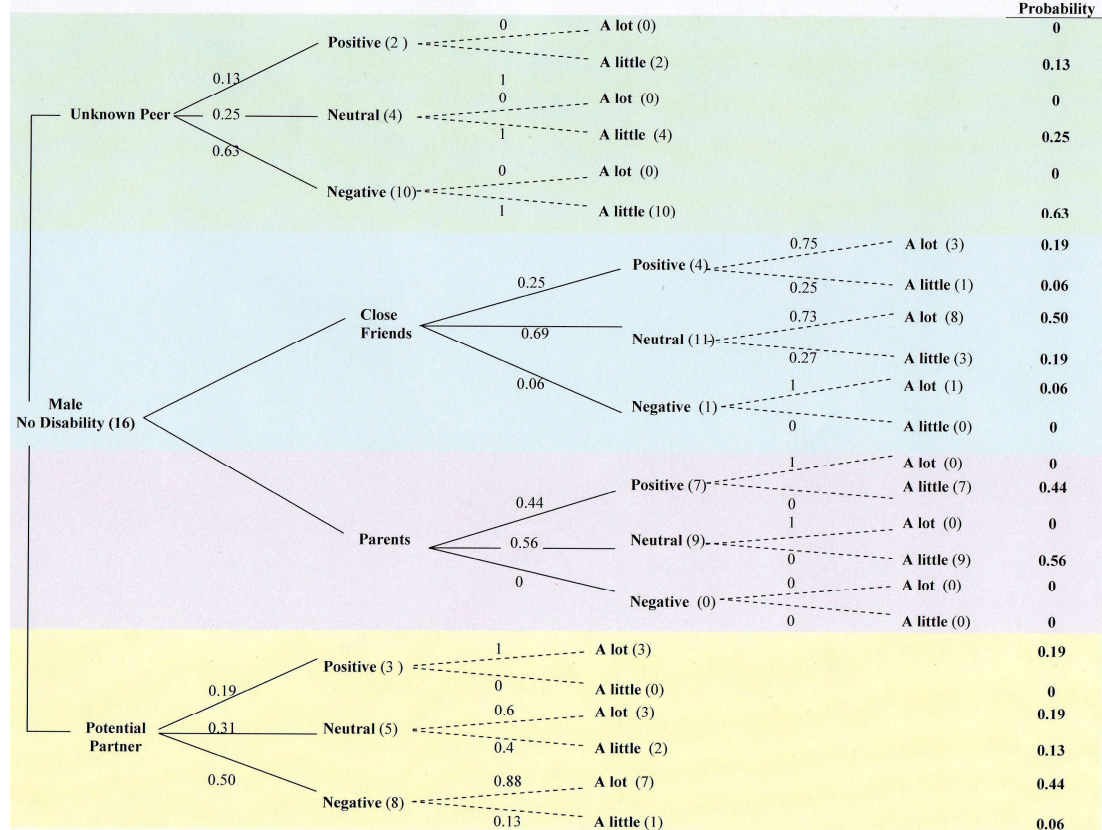


Figure 10.14: Probability tree diagrams for value placed on expected evaluations for *NOT leaving* with the character– No Disability Group, females

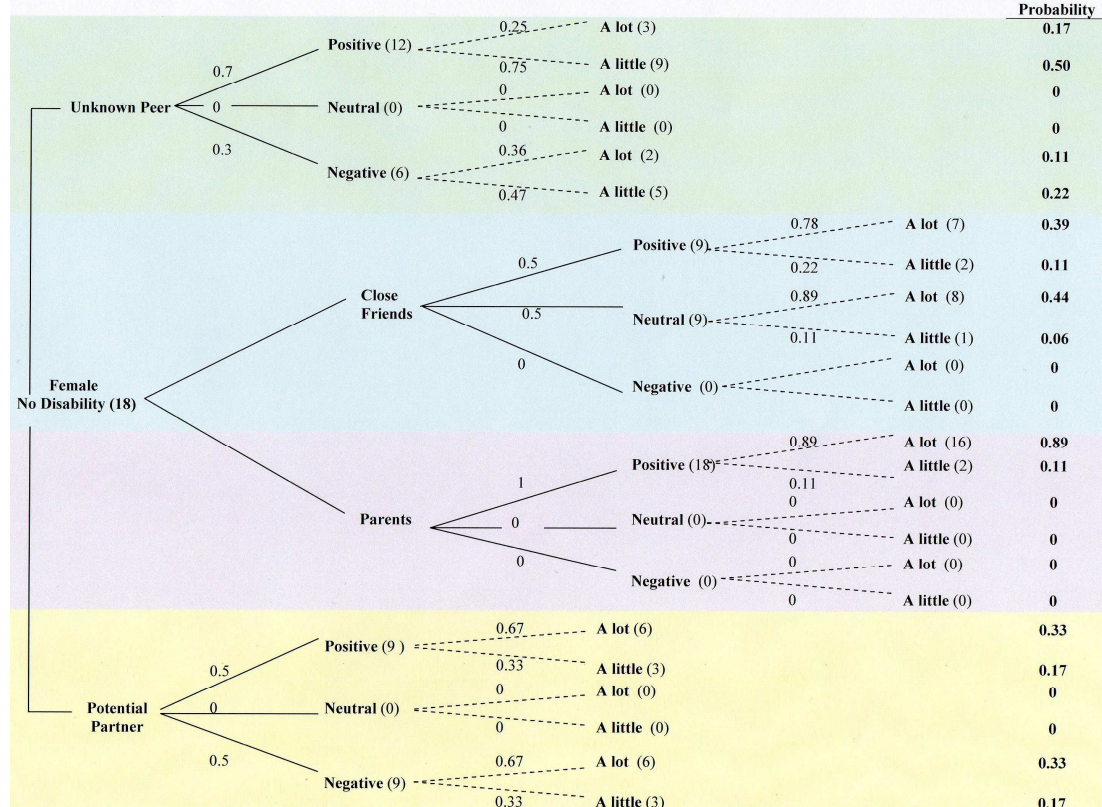


Figure 10.15: Probability tree diagrams for value placed on expected evaluations for *NOT leaving* with the character– Intellectual Disability Group, males

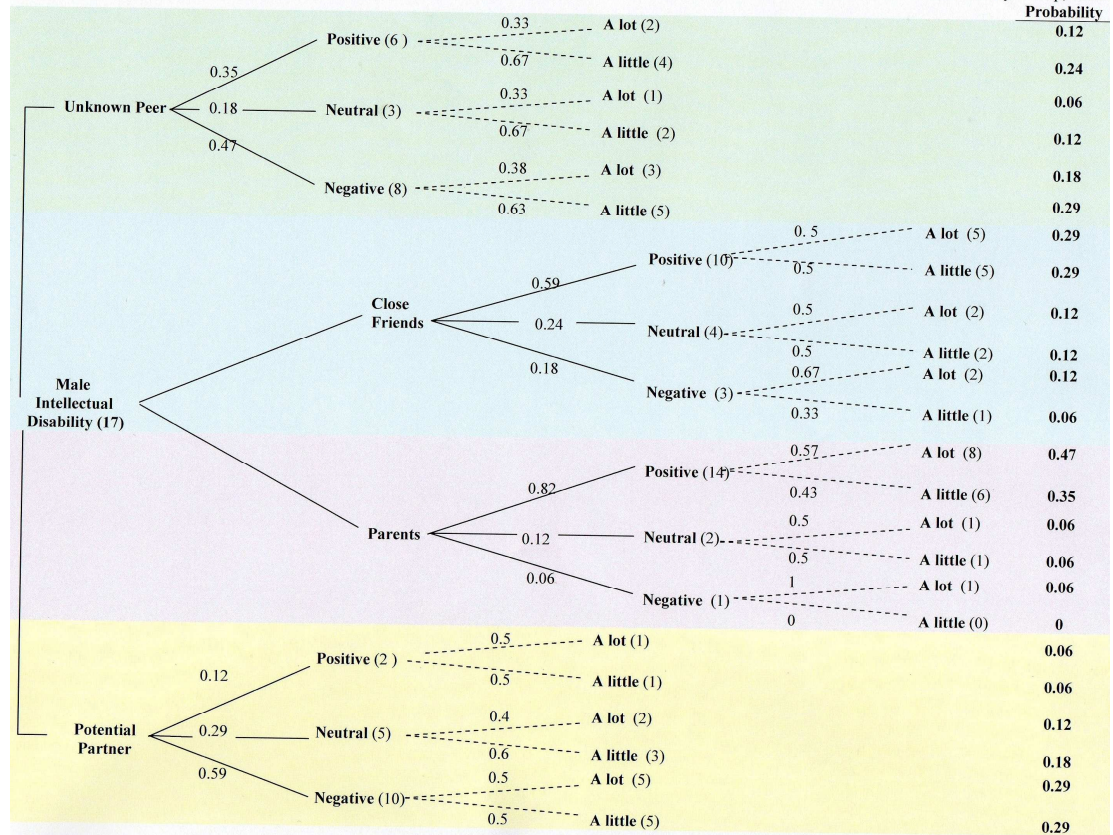


Figure 10.16: Probability tree diagram for value placed on expected evaluations for *NOT leaving* with the character–Intellectual Disability Group, female

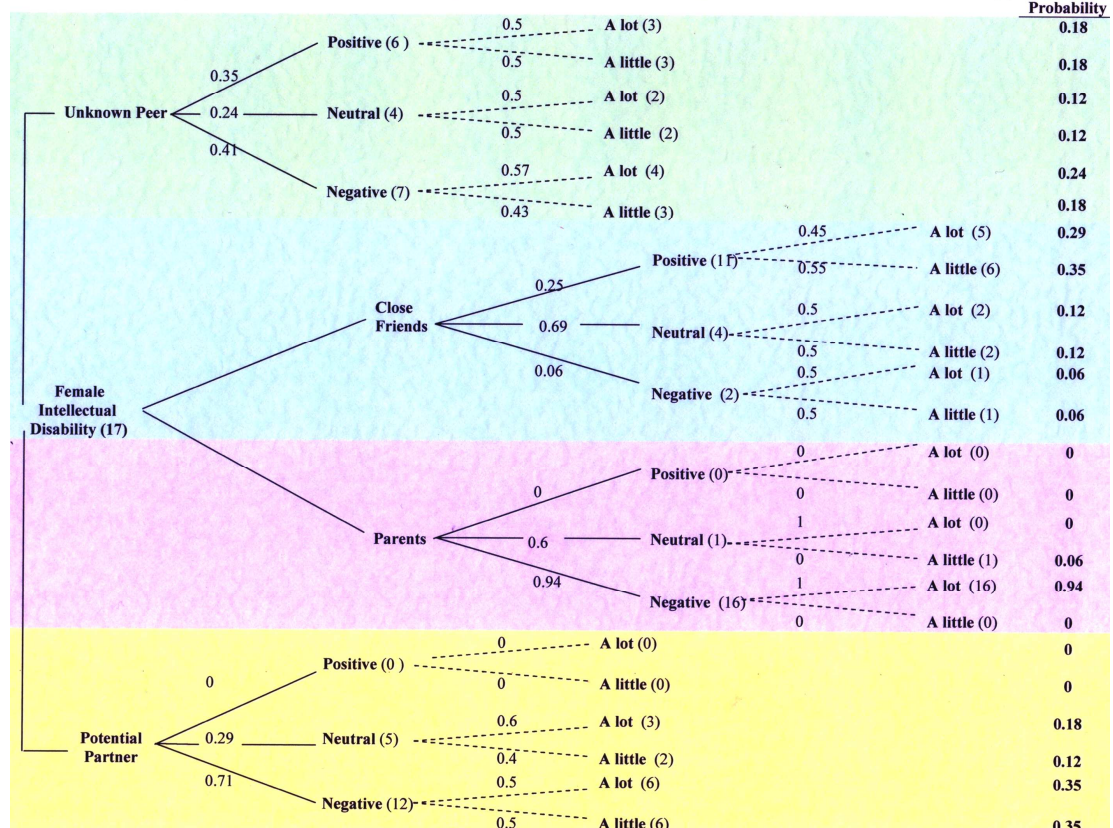


Figure 10.17: Probability tree diagrams for value placed on expected evaluations for *NOT leaving* with the character– Physical Disability Group, males

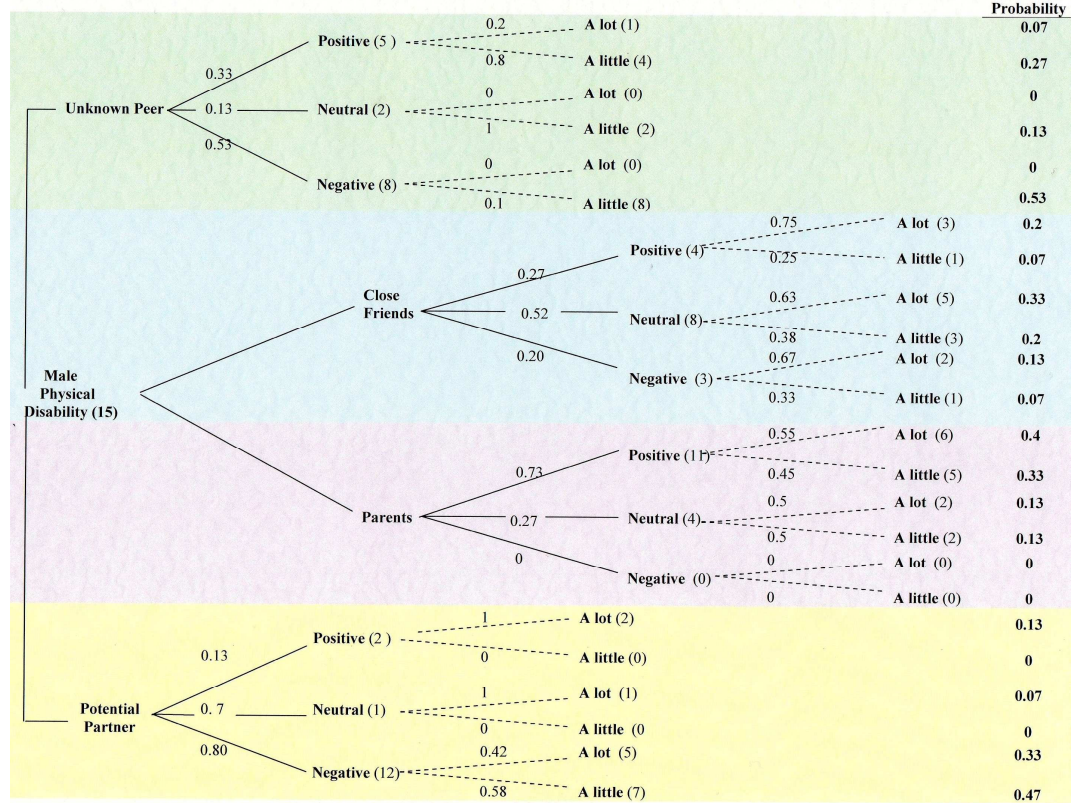


Figure 10.18: Probability tree diagrams for value placed on expected evaluations for *NOT leaving* with the character– Physical Disability Group, females

